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TABLE OF CONTENTS

ARTICLES

147 Reimagining the Risk of Long-Term Care

Allison K. Hoffman

**233 Rehabilitation, Education, and the Integration of Individuals
with Severe Brain Injury into Civil Society: Towards an
Expanded Rights Agenda in Response to New Insights from
Translational Neuroethics and Neuroscience**

Megan S. Wright & Joseph J. Fins

NOTE

289 An Evidence-Based Objection to Retributive Justice

Brian T.M. Mammarella

COMMENTARY

327 A Breakthrough with the TPP: The Tobacco Carve-Out

Sergio Puig & Gregory Shaffer

Reimagining the Risk of Long-Term Care

Allison K. Hoffman *

Abstract:

U.S. law and policy on long-term care fail to address the insecurity American families face due to prolonged illness and disability—a problem that grows more serious as the population ages and rates of disability rise. This Article argues that, even worse, we have focused on only part of the problem. It illuminates two ways that prolonged disability or illness can create insecurity. The first arises from the risk of becoming disabled or sick and needing long-term care, which could be called “care-recipient” risk. The second arises out of the risk of becoming responsible for someone else’s care, which I call “next-friend” risk. The law and social welfare policy has focused on the first, but this Article argues that the second equally threatens the wellbeing of American families. While attempting to mitigate care-recipient risk, in fact, the law has steadily expanded next-friend risk, by reinforcing a structure of long-term care that relies heavily on informal caregiving. Millions of informal caregivers face financial and nonmonetary harms that deeply threaten their own long-term security. These harms are disproportionately experienced by people who are already vulnerable—women, minorities, and the poor. Scholars and policymakers have catalogued and critiqued these costs but treat them as an unfortunate byproduct of an inevitable system of informal care.

This Article argues that if we, instead, understand becoming responsible for the care of another as a social risk—just as we see the chance that a person will need long-term care as a risk—it could fundamentally shift the way we approach

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long-term care policy. In risk-theory terms, this Article proposes we reimagine the risk of long-term care.

TABLE OF CONTENTS

TABLE OF CONTENTS	149
INTRODUCTION.....	151
I. THE EVOLUTION OF LONG-TERM CARE LAW AND POLICY FROM THE CARE-RECIPIENT PERSPECTIVE	157
A. THE FAILURE OF PRIVATE INSURANCE FOR LONG-TERM CARE.....	158
B. THE EVOLUTION AND LIMITS OF SOCIAL INSURANCE FOR LONG- TERM CARE	159
1. THE EMERGENCE OF SOCIAL POLICY ON LONG-TERM CARE	161
2. MEDICAID AND THE MODERN ERA OF SOCIAL INSURANCE.....	162
3. MEDICAID’S RECENT SHIFT: CARE RETURNS HOME.....	165
C. THE RESULTING STRUCTURE OF LONG-TERM CARE	168
II. REIMAGINING LONG-TERM CARE RISK FROM THE NEXT-FRIEND PERSPECTIVE.....	171
A. LONG-TERM CARE AS A PRIVATE OBLIGATION.....	174
1. SOCIAL NORMS AND LONG-TERM CARE	175
2. THE NUMBERS ON INFORMAL CAREGIVING	180
B. OBLIGATION IN A CHANGING WORLD.....	182
C. THE COST OF PRIVATE OBLIGATION: THE INVISIBLE COPAYMENT	184
D. REIMAGINING PRIVATE OBLIGATION AS SOCIAL RISK	188
E. THE IMPLICATIONS OF IMAGINING NEXT-FRIEND RISK	192
III. SOCIAL INSURANCE FOR NEXT-FRIEND RISK.....	195
A. THE CASE FOR SOCIAL INSURANCE FOR NEXT-FRIEND RISK.....	195
B. PRINCIPLES TO GUIDE THE DESIGN OF SOCIAL INSURANCE FOR NEXT-FRIEND RISK	198
C. POLICYMAKING AND DYNAMIC EFFECTS.....	201
D. CONSIDERATIONS FOR WHAT COUNTS AS NEXT-FRIEND RISK.....	204
1. WHO BEARS NEXT-FRIEND RISK?	205
2. DISTINGUISHING RISK FROM ROUTINE.....	210

3. DOES FINANCIAL STATUS QUO MATTER?	211
E. OBJECTIONS TO INSURING NEXT-FRIEND RISK	214
IV. A BRIEF SKETCH OF POLICY OPTIONS.....	219
A. ENVISIONING NEXT-FRIEND SOCIAL INSURANCE	219
1. THE BASIC CONCEPT.....	219
2. MODELS FOR NEXT-FRIEND SOCIAL INSURANCE	223
B. INCREMENTAL REFORMS	225
1. FILLING IN MEDICAID’S GAPS	226
2. EXPANDING AND DESIGNING POLICY TOGGLES IN MEDICAID CONSUMER-DIRECTED CARE PROGRAMS	226
3. INVESTMENTS IN INFRASTRUCTURE	228
4. RESHAPING THE SOCIAL AND INSTITUTIONAL BASELINE	230
CONCLUSION	231

INTRODUCTION

Americans' need for long-term care poses a daunting public policy challenge.¹ The actual demand for care has grown as the rates of disability increase, as modern medicine saves people who previously would not have survived, and as the number of "old old" Americans grows.² An underlying panic about the impending long-term care crisis bubbles up regularly in the news.³ Private efforts to address it have fallen short. Even the social insurance program for long-term care that Ted Kennedy ushered through as part of the Patient Protection and Affordable Care Act (ACA),⁴ called the CLASS Act,⁵ collapsed.⁶ Congress then tasked a Long-Term Care Commission to generate a new solution, and the Commission failed to reach consensus.⁷ Long-term care policy is in limbo.

¹ Long-term care—sometimes called “long-term services and supports”—refers to assistance for someone with chronic illness or disability who faces physical or cognitive limitations. The law defines this care in terms of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs include personal care, such as bathing, dressing, getting in and out of bed, mobility, eating, and toileting. IADLs include more complex functions, including managing finances, managing medication, and shopping. INST. OF MED., *THE FUTURE OF DISABILITY IN AMERICA* 50 (2007) [hereinafter IOM, *FUTURE OF DISABILITY*]. This Article's discussion of long-term care refers to assistance with ADLs and IADLs, not to home health care or medical care (although, as discussed herein, the lines blur at times).

² See Section II.B for discussion of other factors that have increased the need for long-term care. “Old old” generally refers to people over 80 years old.

³ See, e.g., Jason Kane, *6 Tips for Averting America's Looming Long-Term Care Crisis*, PBS NEWSHOUR (Nov. 6, 2013); Bob Kerrey, *Long-Term Solutions... ..for Long-Term Care*, CHI. TRIBUNE (Nov. 21, 2008), http://articles.chicagotribune.com/2008-11-21/news/0811200685_1_quality-long-term-care-providers-health-care; Penelope Wang, *The Retirement Crisis Nobody Talks About: Long Term Care*, TIME (June 20, 2014), <http://time.com/money/2901647/the-retirement-crisis-nobody-talks-about-long-term-care>; John F. Wasik, *Long-Term Care Insurance Can Baffle, With Complex Policies and Costs*, N.Y. TIMES (Dec. 19, 2015), <http://www.nytimes.com/2015/12/19/your-money/long-term-care-insurance-can-baffle-with-complex-policies-and-costs.html>.

⁴ Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111-148, 124 Stat. 119, amended by Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029.

⁵ Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111-148, § 8002(a) 124 Stat. 119, 828-41 (creating Title XXXII of the Public Health and Safety Act).

⁶ The Obama Administration put the program on hold and Congress repealed it because they said it was actuarially unsound. American Taxpayer Relief Act of 2012, Pub. L. No. 112-240, § 642, 126 Stat. 2313, 2358 (2013).

⁷ *Examining the Finance and Delivery of Long-Term Care in the US: Hearing Before Subcomm. On Health of the H. Comm. on Energy & Commerce*, 114th Cong. (2016) (testimony of Alice M. Rivlin, Co-Chair, Long-Term Care Initiative, Bi-Partisan Policy Center).

Policymakers and scholars who have wrestled with social policy for long-term care primarily consider the problem from the perspective of the ten million Americans who need such care—in other words from the perspective of care-recipient risk. Yet the need for long-term care undermines the security of American families in reverberating ways.

This Article argues that the full insecurity of long-term care becomes clear only when we look at the problem also from the perspective of the family and friends who are responsible for providing this care. These informal caregivers are experiencing what this Article proposes we think of as “next-friend” risk.⁸

The early to mid-twentieth century marked a period of decreased reliance on family for long-term care, as social insurance infrastructure developed. Local, state, and federal governments funded care in public institutions and private nursing homes. Yet, late twentieth century law and policy, especially with the creation and evolution of Medicaid, turned the tide back toward older traditions of family caregiving and has resulted in a legal structure that institutionalizes and intensifies caregiving burdens for American families.

Medicaid has become the locus of social insurance for long-term care, financing sixty percent of all paid long-term care.⁹ Because Medicaid eligibility is means-tested, Americans must have almost no income or assets to qualify.¹⁰ That, plus the fact that few people have any private insurance coverage for long-term care, means that most Americans have only two choices: “spend down” their savings to become poor enough to qualify for Medicaid or, more often, rely on family and friends.

Yet, even the people eligible for Medicaid increasingly rely on friends and family for significant amounts of care. Over the past few decades, Medicaid funding for long-term care has shifted from having a bias for care in

⁸ I borrow the phrase “next friend” from the legal term for a person in litigation who represents someone with a disability who is otherwise unable to represent himself. In the context of long-term care, although not necessarily a legal guardian, the next friend protects the interests of another, by providing care directly or arranging it. I use this term instead of “informal caregiver” or “family caregiver” to emphasize that the next friend might not provide care personally (instead helping to outsource it) and is sometimes, although less frequently, a non-relative.

⁹ Carol V. O’Shaughnessy, *National Spending for Long-Term Services and Supports (LTSS)*, 2012, NAT’L HEALTH POL’Y FORUM 3 (2014), https://www.nhpf.org/library/the-basics/Basics_LTSS_03-27-14.pdf (excluding Medicare post-acute care). Medicaid, while it might have once been arguably an entitlement program, has over time increasingly resembled a social insurance program, spreading health spending risk across a growing population of beneficiaries, especially when considering long-term care since the program is universal for anyone who depletes assets to qualify, as discussed *infra* note 70.

¹⁰ See *infra* note 70 (describing Medicaid’s eligibility rules).

institutions to a bias for care in homes. Now, one-half of Medicaid long-term care spending pays for home-based care.¹¹

The conventional wisdom is that this trend is wholly positive.¹² It has decreased reliance on poor-quality institutional care, and it enables many people with serious illness or disability to live at home as independently as possible. On the other hand, Medicaid's evolving approach amplifies burdens for beneficiaries' family and friends.

Medicaid programs for home-based care are underfunded and have long waiting lists and gaps. These programs often limit personal care services and the other non-medical aspects of caregiving that have long been neglected in social welfare programs. Family and friends fill these gaps—gaps that were not as acute in the era of institutional care. At the end of the twentieth century, the law has thus re-inscribed long-term care as a private obligation.

Yet long-term care as a private obligation is increasingly untenable. The actual care needs of people with chronic illness and disability are becoming more intensive.¹³ At the same time, families and friends are less able to address these needs. The breadwinner family structure, where the husband earned wages and the wife took care of the home and family, has eroded. Single-parent families and two wage-earner households are the new normal, leaving little cushion to absorb caregiving.¹⁴ Families have dispersed geographically.¹⁵ And the ratio of people needing care to those who can provide it is increasing as people live longer and have fewer kids.¹⁶

As a result of increased obligations combined with the changing shape of families, informal caregivers, who are disproportionately women, face

11 Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2013: Home and Community-Based Services Were a Majority of LTSS Spending*, CTRS. FOR MEDICARE & MEDICAID SERVS. 3 (2015), <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/ltss-expenditures-fy2013.pdf> (documenting that home and community-based services accounted for 51.3% of total Medicaid spending on long-term services and supports in 2013).

12 See, e.g., Sidney D. Watson, *From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid's History*, 26 GA. ST. U. L. REV. 937, 937-38, 967-68 (2010) (describing this trend and the benefits of increased home-based care).

13 See note 185 *infra* and accompanying text.

14 See U.S. CENSUS BUREAU, STATISTICAL ABSTRACT OF THE U.S.: 2012, 840 tbl. 1337 (2012) (documenting the rise in single-parent households); Howard N. Fullerton, Jr., *Labor Force Participation: 75 Years of Change, 1950-98 and 1998-2025*, 1999 MONTHLY LAB. REV. 3, 4 tbl. 1 (documenting the past and projected increasing participation of women in the U.S. labor force).

15 See Ping Ren, U.S. Census Bureau, *Lifetime Mobility in the United States: 2010*, U.S. CENSUS BUREAU 1, 3 (2011) ("The U.S. population is characterized by high mobility.").

16 See Emily Brandon, *65-and-Older Population Soars*, U.S. NEWS (Jan. 9, 2012, 9:15 AM), <http://money.usnews.com/money/retirement/articles/2012/01/09/65-and-older-population-soars> (reporting that the proportion of Americans 65 and older has grown from 4.1% in 1900 to 13% in 2012).

staggering burdens.¹⁷ By one estimate, the financial losses alone—including forgone income, pensions, benefits, and retirement savings—sustained by the average informal caregiver who leaves the workforce to care for a parent are \$300,000.¹⁸ These monetary losses are just the beginning. Many informal caregivers experience permanent harm to their health, relationships, and general wellbeing.¹⁹

What if instead of designating these costs as a private obligation, we considered them as a collective problem—the manifestation of a social risk? While caregiving might have been excluded from the American vision of social insurance at its nascence, when it was perceived as not posing a threat to the security of the breadwinner family, long-term care is clearly a serious threat to the security of American families now and should be recognized as such.

This Article offers a new possibility: considering the burdens of caregiving, at least with respect to long-term care, as a serious social risk—one equal to the risk of needing long-term care. This perspective could offer insights for two areas of legal scholarship. First, a considerable body of health, elder, and disability law and policy scholarship addresses long-term care as a social insurance problem, but it assumes the primary insurable risk is care-recipient risk.²⁰ Implicit in this work is, in most cases, the inevitability of continued, substantial reliance on informal caregiving—a position this Article questions. In contrast, a rich body of feminist legal scholarship demands greater state support for caregiving, mostly with regard to childcare but to some extent also long-term care, based on ideas that caregiving is a public responsibility or a public good.²¹ Seeing the burdens next friends face as a social risk provides another justification for enhanced state support, and, even more importantly, reframing the costs caregivers face in the language of risk justifies social insurance to address these costs.²²

¹⁷ See *infra* Section II.C.

¹⁸ METLIFE MATURE MARKET INST., THE METLIFE STUDY OF CAREGIVING COSTS TO WORKING CAREGIVERS: DOUBLE JEOPARDY FOR BABY BOOMERS CARING FOR THEIR PARENTS 15 (2011) [hereinafter METLIFE, DOUBLE JEOPARDY], <https://www.metlife.com/assets/cao/mmi/publications/studies/2011/Caregiving-Costs-to-Working-Caregivers.pdf>. Another recent study models the median opportunity costs of two years of caregiving for a sick mother to be \$164,726. Meghan M. Skira, *Dynamic Wage and Employment Effects of Elder Parent Care*, 56 INT'L ECON. REV. 63, 82 (2015). Since the average duration of caregiving is twice as long, see *infra* note 182 and accompanying text, the average caregiver would face opportunity costs twice this amount.

¹⁹ METLIFE, *supra* note 18, at 15.

²⁰ See *infra* notes 122-123 and accompanying text.

²¹ See *infra* notes 125-126.

²² Anne Alstott's "life-planning insurance" is a form of social insurance for parents of children with disabilities. ANNE ALSTOTT, NO EXIT 117-37 (2004). She justifies her proposal

The language of risk is powerful. How a society understands risk strongly shapes perceptions of the proper role of the state.²³ Every creation or expansion of social insurance in the United States required reimagining something that had previously been thought of as a private cost or obligation instead as a social risk—a threat to American families’ security—in order to motivate a collective solution.²⁴

The costs and obligations next friends shoulder look very similar to other insurable risks. Responsibility for the long-term care of another is unplanned and often unavoidable. The level of harm is stochastic and unmanageable for almost all Americans in the worst-case scenario involving years of intensive care. This responsibility threatens Americans’ financial, emotional, and physical wellbeing as much as other phenomena that have motivated government response, including work injuries, unemployment, outliving one’s savings, and medical spending in retirement.²⁵ Taking next-friend risk seriously has at least four major implications for long-term care policies.

based on public responsibility owed to these parents in return for their heightened caregiving obligation. This Article could support a similar intervention but based on a different rationale—the existence of a widely shared social risk. This rationale suggests the need for a social insurance solution available to any friend or family member who takes on the responsibility of another’s long-term care, not just to parents.

23 The language of risk is increasingly used to evoke an individual’s responsibility to reduce risk through responsible choices, but historically it described problems that warranted a collective solution. *See, e.g.*, JACOB HACKER, *THE GREAT RISK SHIFT* (2006) (describing what he calls the “personal responsibility crusade” and how it has created insecurity for American families by undermining social insurance policies); Tom Baker & Jonathan Simon, *Embracing Risk*, in *EMBRACING RISK* (Tom Baker & Jonathan Simon eds., 2002) (describing both an increased recognition of social problems in terms of risk and a reactionary trend against spreading risk); Martha McCluskey, *Rhetoric of Risk and Redistribution of Social Insurance*, in *EMBRACING RISK*, *supra*, at 146 (describing a shift in the United States from concern with the risk faced by workers to that faced by employers and big business); Jonathan Simon, *Risk and Reflexivity: What Socio-Legal Studies Add to the Study of Risk and the Law*, 57 ALA. L. REV. 119 (2005) (describing the evolution of the risks that most concern Americans and changing beliefs on how best to manage risk).

24 Examples of scholarship that describe how an understanding of risk has motivated state action to ameliorate it include MICHELE LANDIS DAUBER, *THE SYMPATHETIC STATE: DISASTER RELIEF AND THE ORIGINS OF THE AMERICAN WELFARE STATE* (2013); MICHAEL A. GRAETZ & JERRY L. MASHAW, *TRUE SECURITY: RETHINKING AMERICAN SOCIAL INSURANCE* (1999); THEODORE R. MARMOR ET AL., *SOCIAL INSURANCE: AMERICA’S NEGLECTED HERITAGE AND CONTESTED FUTURE* (2014); DAVID A. MOSS, *WHEN ALL ELSE FAILS: GOVERNMENT AS THE ULTIMATE RISK MANAGER* (2002); JOHN FABIAN WITT, *THE ACCIDENTAL REPUBLIC: CRIPPLED WORKINGMEN, DESTITUTE WIDOWS, AND THE REMAKING OF AMERICAN LAW* (2004); Baker & Simon, *supra* note 23; François Ewald, *The Return of Descartes’s Malicious Demon: An Outline of a Philosophy of Precaution* (Stephen Utz trans.), in *EMBRACING RISK*, *supra* note 23, at 278-81; and Michele L. Landis, *Fate, Responsibility, and ‘Natural’ Disaster Relief: Narrating the American Welfare State*, 33 L. & SOC’Y REV. 257, 271 (1999).

25 These programs are addressed by a mix of mandatory private insurance and social insurance, but they share in common that social policy requires risk to be shared collectively,

First, it redefines the scale of the problem of long-term care. Current policy hides costs borne by next friends, in ways described in Part I below. In 2013, by one conservative estimate, informal caregivers provided \$470 billion worth of long-term care services to adults, if time spent caregiving were valued at market caregiver wages.²⁶ Accounting for replacement costs for just these hours—only a part of the problem—would require additional funding of triple Medicaid’s current spending on long-term care. Even if this level of additional funding is unlikely, considering these costs as part of the problem could at least anchor policymakers on a higher number and a more complete view of the costs of long-term care, as discussed in Part II.

Second, understanding these costs as a manifestation of next-friend risk implies that social insurance might be the best tool to address the problem.²⁷ Part III makes the case for better social insurance protections against next-friend risk and considers conceptually what it would require to create such protections. This Part examines where next-friend risk begins and ends and for whom.

Third, whether with additional funding or not, policies could be designed to better mitigate next-friend risk, as discussed in Part IV. There are two ways that a next friend could, in theory, respond to another’s need for care: provide it personally or pay for care. If she could toggle more freely between these two choices—provide or pay—she could determine how to use benefits simultaneously to minimize her own harm and to meet the needs of the person who needs long-term care. Current policy is focused so narrowly on care-

rather than borne privately.

26 Susan C. Reinhard et al., *Valuing the Invaluable: 2015 Update, Undeniable Progress, but Big Gaps Remain*, AARP PUB. POL’Y INST. 3 (2015). Note that this estimate, based on eleven surveys of family caregivers, only accounts for care recipients age 18 and older and uses an hourly wage of \$12.51. Other estimates are higher and lower. One study estimates opportunity costs of \$412 billion for informal elder caregivers under the age of 65 (\$522 billion if also including those over age 65). Amalavoyal V. Chari et al., *The Opportunity Costs of Informal Elder-Care in the United States: New Estimates from the American Time Use Survey*, 50 HEALTH SERVS. RES. 871, 877 (2015). The same study estimates replacement costs ranging from \$221 to 642 billion, depending on whether skilled or unskilled labor is used (\$7.25 per hour for the former estimate and \$21 per hour for the latter). *Id.*

27 “Social insurance” is used to refer to government programs that spread risk, such as Medicare or Social Security. See MARMOR ET AL., *supra* note 24. Because social insurance also intentionally redistributes resources, some argue that it is actually a tax-and-transfer program and not like “real” (meaning private) insurance. See James Kwak, “Social Insurance,” *Risk Spreading, and Redistribution*, in RESEARCH HANDBOOK ON THE ECONOMICS OF INSURANCE LAW 127 (Daniel Schwarcz & Peter Siegelman eds., 2015). This view, however, fails to recognize that all insurance, private and public, is redistributive from low-risk to high-risk people and from the lucky to the unlucky. Pricing can attempt to limit this redistribution or to counterbalance regressivity that ensues, but regardless of the extent, redistribution is a defining feature of all insurance.

recipient risk that it does not even see the need for this toggle and often prevents it.

Fourth, recognizing next-friend risk forces the admittedly uncomfortable question of whether social policy must better balance the needs of care recipients and next friends.

It is not easy to conceive of a solution to the long-term care problem when seen from both the care-recipient and next-friend perspectives, because of its sheer magnitude and complexity. But turning a blind eye to the costs borne by next friends by hiding these costs in homes across the country is not a sustainable solution. Any social insurance policy for long-term care—whether comprehensive or not—must at least grapple with the reverberating ways that long-term care needs undermine Americans’ security; otherwise, policies will, in the process of creating security for some, bolster social structures that undermine security for others.

I. THE EVOLUTION OF LONG-TERM CARE LAW AND POLICY FROM THE CARE-RECIPIENT PERSPECTIVE

The existence of insurance for long-term care is a relatively recent phenomenon. Before the twentieth century, long-term care was the responsibility of family or community.²⁸ This notion of familial responsibility, however, has been an ambivalent one in the United States since at least the mid-nineteenth century, when a “society defined by mobility and free labor” weakened presumptions of family obligation.²⁹ As a result, other forms of providing and paying for long-term care slowly began to emerge.

Long-term care insurance—both private and social—has had mixed results. Private long-term care insurance has largely failed and, experts agree, would be challenging to revive.³⁰ Social insurance has evolved and expanded but is still piecemeal and partial.³¹ Despite limited reach, both private and social long-term care insurance work, in theory, to cushion the harms people suffer when they face chronic illness or physical or mental disability. In other words, both aim to mitigate care-recipient risk. Policies can pay for variable amounts of help with personal care, such as bathing, dressing, getting in and out of bed, eating, and using the toilet—collectively referred to as the

²⁸ See David Barton Smith & Zhanlian Feng, *The Accumulated Challenges of Long-Term Care*, 29 HEALTH AFF. 29, 29 (2010).

²⁹ HENDRICK HARTOG, *SOMEDAY ALL THIS WILL BE YOURS: A HISTORY OF INHERITANCE AND OLD AGE* 29 (2012).

³⁰ See Jeffrey R. Brown & Amy Finkelstein, *Insuring Long-Term Care in the U.S.*, 25 J. ECON. PERSP. 119, 129-31 (2011).

³¹ See generally EILEEN BORIS & JENNIFER KLEIN, *CARING FOR AMERICA: HOME HEALTH WORKERS IN THE SHADOW OF THE WELFARE STATE* (2012) (describing the evolution of the government’s role in paying for caregiving).

Activities of Daily Living (ADLs)—and also with more complex functions, such as managing finances, household chores, medication, and shopping—collectively, Instrumental Activities of Daily Living (IADLs).³²

This Part describes the emergence of long-term care insurance and how, in the end, Medicaid became the primary locus of public long-term care funding. It illustrates how the development of Medicaid policy from the care-recipient perspective has provided greater security for some people with disabilities and illness, but, at the same time, has increased and cemented reliance on friends and family to meet care-recipients' long-term care needs.

A. *The Failure of Private Insurance for Long-Term Care*

Private insurance struggles under classic conditions of market failure.³³ Only seven to nine million Americans in 2010 held private long-term care insurance policies.³⁴ Experts attribute the low penetration rate of private long-term care insurance to both perception and prices. Research shows that people undervalue the purchase of long-term care insurance due to poor information or cognitive biases that cause them to underestimate their future long-term care needs.³⁵ This undervaluation is compounded by the high price of policies, caused in part by pervasive adverse selection (i.e., people who buy policies are more likely to use them).³⁶

Even without such problems, many people would still forgo private coverage. For low- and middle-income people, who might become eligible for Medicaid, its existence as a safety net crowds out private coverage.³⁷ For

32 IOM, *FUTURE OF DISABILITY*, *supra* note 1, at 50. I discuss below in Section II.E. why mitigating care-recipient risk does not necessarily mean simultaneously mitigating risk for next friends, based on both the comprehensiveness and the particular design of long-term care insurance.

33 See Brown & Finkelstein, *supra* note 30, at 129.

34 See Kathleen Ujvari, *Long-Term Care Insurance: 2012 Update*, AARP PUB. POL'Y INST. 1 (2012), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/ltc-insurance-2012-update-AARP-ppi-ltc.pdf.

35 See Brown & Finkelstein, *supra* note 30, at 131; Jeffrey R. Brown, et al., *Long-Term Care Insurance Demand Limited by Beliefs About Needs, Concerns About Insurers, and Care Available from Family*, 31 HEALTH AFF. 1294, 1300 (2012).

36 See Brown & Finkelstein, *supra* note 30, at 126-28; Mark J. Browne, *Adverse Selection in the Long-Term Care Insurance Market*, in INSURANCE: THEORETICAL ANALYSIS AND POLICY IMPLICATIONS 97 (Pierre-André Chiappori & Christian Gollier eds., 2006); Emily Oster et al., *Genetic Adverse Selection: Evidence from Long-Term Care Insurance and Huntington Disease*, 94 J. PUB. ECON. 1041 (2010) (showing selection among people with Huntington Disease into long-term care insurance markets).

37 See Jeffrey R. Brown & Amy Finkelstein, *The Interaction of Public and Private Insurance: Medicaid and the Long-Term Care Insurance Market*, 98 AM. ECON. REV. 1083,

those unlikely to qualify for Medicaid, the decision not to buy long-term care insurance might be a way for aging parents to ensure family members will care for them personally, in their homes, rather than use policy benefits to put them in a nursing home.³⁸ Since private insurance generally does not pay for family care, having private insurance is less appealing to people who prefer that a family member or close friend provide care.³⁹

Because of these problems, the current private market is unraveling. Premium rates are unstable and for some policies the benefits are not guaranteed or inflation protected.⁴⁰ Even in the best case, benefits are typically insufficient to pay for all necessary care, especially for someone who wants to receive care at home.⁴¹ One expert notes that “the prospective insured must have access to a dependable network of family, friends, and others to supplement the [paid] home care provider if she expects to use the policy’s benefits for home care.”⁴²

In light of these challenges, many major insurers are terminating their business in long-term care.⁴³ Several attempts to revive the market, through tax incentives and programs that offer people who purchase private policies Medicaid eligibility with greater asset protection, have had little effect.⁴⁴ There may be ways to reverse this trend,⁴⁵ but to the extent the private insurance market continues to struggle, social insurance offers the only viable option for long-term care insurance for most Americans.

B. The Evolution and Limits of Social Insurance for Long-Term Care

Long-term care has not fit easily into the particular American vision of social insurance either and, as a result, social insurance policies to address long-term care needs have been incremental and incomplete. President Theodore Roosevelt described the goal of social insurance as protection

1092-93 (2008).

38 Mark V. Pauly, *The Rational Nonpurchase of Long-Term-Care Insurance*, 98 J. POL. ECON. 153, 163 (1990).

39 Corina Mommaerts, Long-Term Care Insurance and the Family (Nov. 11, 2015) (unpublished manuscript) (draft on file with author) (showing that informal care by family members weakens demand for long-term care insurance).

40 Insurers are prohibited from raising rates for individual policyholders, but they can and have raised rates for an entire class of policies, doubling or even tripling premiums and causing policyholders to drop coverage. See Richard L. Kaplan, *Retirement Planning’s Greatest Gap: Funding Long-Term Care*, 11 LEWIS & CLARK L. REV. 407, 440 (2007).

41 *Id.* at 432.

42 *Id.*

43 *Id.* at 442.

44 *Id.* at 443-48. Because any assets in excess of insurance benefits must be depleted and the home equity limits still apply, this program really only targets those just above Medicaid thresholds. *Id.*

45 See Brown & Finkelstein, *supra* note 30; Brown & Finkelstein, *supra* note 37.

against the “hazzards [sic] of sickness, accident, invalidism, involuntary unemployment and old age.”⁴⁶ These hazards shared the common feature of threatening the family wage due to a breadwinner’s inability to work.⁴⁷ The role of social insurance, in turn, was to replace lost wages. Long term-care was not seen as a threat to the family wage. Non-medical caregiving was perceived as being absorbed seamlessly into a breadwinner household structure by the non-wage-earning wife.⁴⁸ Even medical care was relatively inexpensive and often ineffective at the time when social insurance first emerged.⁴⁹ As a hybrid of medical care and caregiving, long-term care was a low priority for early social policy efforts.

Over time, however, social policies took up long-term care, and Medicaid eventually emerged as the locus for long-term care social insurance policy. To be clear, a variety of other government programs address other needs of people with chronic illness or disability by, for example, replacing a portion (albeit small) of lost wages through disability insurance⁵⁰ or paying for medical needs through medical insurance. These programs, while critically important for people with disabilities and chronic illness, do not address or account for their long-term care needs—the assistance that they require on a daily basis.

This Section describes Medicaid’s emergence and evolution, how it has attempted to address the needs of care recipients, and, in the process, how it has reaffirmed and intensified obligations for their friends and family.

46 Theodore Roosevelt, Address Before the Convention of the National Progressive Party in Chicago, Illinois (Aug. 6, 1912) (transcript at <http://www.ssa.gov/history/trspeech.html>).

47 GRAETZ & MASHAW, *supra* note 24, at 212. In the breadwinner family structure, the husband earned the wages and the wife cared for the household and family. *See, e.g.*, ALICE KESSLER-HARRIS, *IN PURSUIT OF EQUITY: WOMEN, MEN AND THE QUEST FOR ECONOMIC CITIZENSHIP IN TWENTIETH CENTURY AMERICA* (2001).

48 BORIS & KLEIN, *supra* note 31; *see also* Andrew I. Batavia et al., *Toward a National Personal Assistance Program: The Independent Living Model of Long-Term Care for Persons with Disabilities*, 16 J. HEALTH, POL’Y & L. 523, 527 (1991) (describing traditional reliance on a system of “informal support” provided by family members and close friends); Katherine C. Pearson, *Filial Support Laws in the Modern Era: Domestic and International Comparison of Enforcement Practices for Laws Requiring Adult Children To Support Indigent Parents*, 20 ELDER L.J. 269, 272 (2012) (describing how filial support laws support this notion of family caregiving). One early exception was the creation of public institutions for the care of the “feeble-minded” in the early 1900s. E. FULLER TORREY, *AMERICAN PSYCHOSIS: HOW THE FEDERAL GOVERNMENT DESTROYED THE MENTAL ILLNESS SYSTEM* 4 (2013).

49 *See* PAUL STARR, *THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE* 383, 388 (1982).

50 Disability benefits, including Social Security Disability, Supplemental Security Income, and Workers Compensation, together replace only 25% of lost income and are insufficient to pay for long-term care needs. *See* GRAETZ & MASHAW, *supra* note 24, at 84.

1. *The Emergence of Social Policy on Long-Term Care*

In the early 1900s, long-term care was “the last holdover of the Elizabethan poor-law approach.”⁵¹ The only public welfare for long-term care was provided in poorhouses, which “amounted to incarceration for destitution.”⁵² Most people remained reliant on family care.⁵³

But over the course of the twentieth century, publicly funded support for long-term care grew. Early efforts at the state and local levels funded the creation of public hospitals, state mental asylums, and schools for the blind and the deaf.⁵⁴ After the Great Depression, the federal government entered into the fold with cash and in-kind assistance programs to support people with disabilities. Federal efforts began in earnest with the Social Security Act of 1935, which included the Old-Age Assistance program (for poor elderly), Aid to the Blind, and Aid to Dependent Children, which were all programs of cash assistance.⁵⁵

These programs ushered in a private nursing home industry. The federal matching funds for institutional care could not be used for “an inmate of a public institution,” including state mental asylums and almshouses.⁵⁶ The availability of this restricted funding spurred the growth of new private institutions that could accept the funds.⁵⁷

Even as nursing home care expanded, home-based care continued with the support of various local, state, and federal efforts including the Works Progress Administration’s “Housekeeping Services.”⁵⁸ These programs funded everything from nursing care to personal care and even housework and childcare, in some cases, for ill or disabled mothers.⁵⁹ The mid-century rise of private medical insurance, however, began to undermine these home-based care programs. Insurance required services that were medical in nature to be performed by licensed providers, which relocated the medical aspects of caregiving from homes to hospitals. The other care-intensive aspects were carved out of medical insurance and left to underfunded state welfare programs.⁶⁰

51 Smith & Feng, *supra* note 28, at 27.

52 *Id.*; see Watson, *supra* note 12, at 940.

53 Even for family members in institutions, women were responsible for taking care of clothing, bedding, and other necessities. BORIS & KLEIN, *supra* note 31, at 20.

54 See Watson, *supra* note 12, at 941.

55 *Id.* at 941-47; Smith & Feng, *supra* note 28, at 31.

56 Watson, *supra* note 12, at 942; see Smith and Feng, *supra* note 28, at 31. The federal mental health legislation in the 1940s similarly prohibited federal funds to be spent on people living in state mental health hospitals. TORREY, *supra* note 48, at 26.

57 Watson, *supra* note 12, at 944.

58 BORIS & KLEIN, *supra* note 31, at 22.

59 *Id.* at 30.

60 *Id.* at 65.

Modeled on this medicalized framework, the 1960 amendments to the Social Security Act, including the Kerr-Mills Act, were the precursor to Medicaid and the beginning of more substantial public funding for long-term care.⁶¹ These amendments expanded eligibility for benefits to the “medically needy”—people who were living above state public assistance levels but spending a large share of their income on medical care—and defined medical assistance to include long-term care.⁶² With an expanded population of eligible beneficiaries and a continued bias toward funding long-term care in private, licensed institutions, the Kerr-Mills Act increased the number of private nursing homes tenfold and laid the conceptual and structural foundation for Medicaid.⁶³

2. *Medicaid and the Modern Era of Social Insurance*

The establishment of Medicare for the elderly and Medicaid for the “deserving poor” in 1965 meant increasing social-insurance coverage of long-term care within the medicalized model.⁶⁴ Although neither program was specifically focused on long-term care, Medicaid became the default social insurance program responsible for it.

Despite the common misconception otherwise, Medicare funds long-term care at best “tangentially,” such as post-acute care after hospitalization, but it does not pay for support with activities of daily living in home settings.⁶⁵ In fact, Medicare was intentionally *not* tailored to the needs of *chronically ill* elderly because the drafters envisioned it would eventually expand into a universal program for all Americans.⁶⁶ Long-term nursing care was excluded

61 Watson, *supra* note 12, at 946-48. The Kerr-Mills Act was officially titled the Medical Assistance for the Aged. Social Security Amendments of 1960, Pub. L. No. 86-778, §§ 601-04, 74 Stat. 924, 987-92.

62 Watson, *supra* note 12, at 948-50.

63 *See id.* at 950-51.

64 Some would refer to Medicaid as a welfare program because it is means-tested, but because it spreads the risk of medical costs among a large portion of the population, it can also be thought of as a form of social insurance. *See supra* note 25.

65 Judith Feder et al., *Long-Term Care in the United States: An Overview*, 19 HEALTH AFF. 40, 44 (2000). Medicare pays for “post-acute” care, including 90 days of hospital care and a portion of another 100 days of care in a skilled nursing facility or nursing home following hospitalization. 42 U.S.C. § 1395x(i) (2012) (requiring hospitalization for at least three days and transfer to the skilled-nursing facility within thirty days). Medicare also has a home-health benefit that includes nursing care and rehabilitative services, such as speech or physical therapy. 42 U.S.C. § 1395x(m) (covering skilled nursing care or rehabilitative services under a plan established by a doctor and reviewed every 60 days). Nursing care is limited to less than 8 hours per day and 28 hours per week and must be provided by or under the supervision of a registered professional nurse. *Id.*

66 *See* MARMOR ET AL., *supra* note 24, at 232-33.

from Medicare altogether because it was deemed more custodial than medical.⁶⁷ One study found that even in cases with Medicare reimbursing home health care, family caregivers still provided three-quarters of needed care, including in half of cases, performing skilled nursing care, such as monitoring blood pressure and symptoms, and providing counseling or physical or speech therapy.⁶⁸ In effect, Medicare is not intended to and does not insure long-term care.

In contrast, Medicaid now finances over sixty percent of all paid long-term care services.⁶⁹ It is a cooperative program between the federal government and the states. Federal regulations dictate eligibility and benefits parameters for the state-run Medicaid programs and have shaped the face of long-term care provision in the United States.

Several aspects of Medicaid's design have been particularly significant. First, even though Medicaid is now the primary financier for paid long-term care, it is available to only the poorest Americans with significant medical need *and* low income and assets.⁷⁰ Covering this population served as a release valve. By addressing the needs of the most vulnerable people, Medicaid alleviated the urgency for a more comprehensive long-term care solution. Most Americans, somewhere in the middle of poor enough to qualify for Medicaid and wealthy enough to afford a private long-term care policy,

⁶⁷ Watson, *supra* note 12, at 956.

⁶⁸ Carole Levine et al., "This Case is Closed": Family Caregivers and the Termination of Home Health Care Services for Stroke Patients, 84 MILBANK Q. 305, 315-16 (2006).

⁶⁹ O'Shaughnessy, *supra* note 9, at 3 (excluding Medicare post-acute care). Individuals finance 22% out of pocket and private insurance finances 12%. *Id.* Other public programs, including the Department of Veterans Affairs or Department of Housing and Urban Development funding for supportive services and housing for elderly or disabled residents of HUD-assisted housing, only financed \$10 billion in long-term care in 2012. JULIE STONE, CONG. RESEARCH SERV., R40718, LONG-TERM CARE (LTC): FINANCING OVERVIEW AND ISSUES FOR CONGRESS 11-13 (2009). The Older Americans Act (OAA) includes in-kind assistance for people living at home; its biggest, called "meals on wheels," provides meals to older people in home settings. Wendy Fox-Grage & Kathleen Ujvari, *The Older Americans Act*, AARP PUB. POL'Y INST. 2 (2014) (reporting that meals on wheels served approximately 2.5 million people in 2011). The total OAA budget was only \$1.88 billion in fiscal year 2014. *Id.* at 3.

⁷⁰ In most states an individual's Medicaid eligibility is tied to eligibility for the Supplemental Security Income (SSI) program, which provides means-tested cash assistance for disabled, blind, or aged individuals. States may extend eligibility to others with higher incomes up to 300% of the federal poverty level. *See* JULIE STONE, CONG. RESEARCH SERV., RL33593, MEDICAID COVERAGE FOR LONG-TERM CARE: ELIGIBILITY, ASSET TRANSFERS, AND ESTATE RECOVERY 4-5 (2008). Some qualify, even if above these income thresholds, by showing high medical bills that effectively deplete or "spend down" their income to eligibility levels. *Id.* at 4. Beneficiaries must also meet low assets standards, which is in most states under \$2000 for an individual and under \$3000 for a couple, excluding some assets, such as a car and some value of a residence. *Id.* at 6-7.

turn to family and friends to fill in the gap (so long as they are fortunate enough to have someone to whom to turn).⁷¹

Second, in the model of the Kerr-Mills Act, Medicaid adopted a medicalized approach.⁷² It initially had an “institutional bias” favoring the provision of long-term care in licensed nursing homes.⁷³ Care in nursing homes and other licensed institutions was designated a mandatory Medicaid benefit—one that states must cover to receive federal matching funds.⁷⁴ In contrast, personal care in home settings (e.g., bathing, dressing, eating, light housework, grocery shopping, etc.) was designated as an optional benefit—states could receive matching funds for this type of care but did not need to cover it.⁷⁵ These rules had two implications. First, Medicaid’s benefit structure created incentives for more long-term care in nursing homes. Second, as Medicaid’s institutional bias receded in favor of home-based care, as described below, states’ programs did not cover all of the services people might need at home, since many were optional benefits.

Finally, because of statutory rules that limited the use of federal matching funds for care in public institutions, Medicaid furthered the dismantling of state public institutions for long-term care and the proliferation of private nursing homes to take their place.⁷⁶ Medicaid made nursing homes a federally funded alternative for people with developmental delays and psychological illness, as well as an option for care for aging parents.⁷⁷ Spending on nursing homes increased exponentially after the passage of Medicaid, from \$46 million in 1960 to \$3.5 billion by 1967.⁷⁸ Medicaid thus significantly reshaped the institutional structure of long-term care.

Medicaid laid the foundation for a system of long-term care where only the poorest Americans were socially insured and where private nursing homes

⁷¹ Long-term care is not included in the typical private health insurance plan. Medigap plans might pay for assistance with ADLs but only in some plans and with a low dollar limit. Kaplan, *supra* note 40, at 421.

⁷² See Smith & Feng, *supra* note 28, at 31.

⁷³ See Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1, 61 (2004).

⁷⁴ See STONE, *supra* note 69, at 7. States must also fund home health care for people who would otherwise be eligible for nursing facility services. 42 U.S.C. § 1396a(a)(10)(D) (2012). Medicaid also adopted the Kerr-Mills eligibility category of medically needy. *Id.* § 1396a(a)(10)(C). Since many medically needy spend down on long-term care, this policy increased the numbers beneficiaries in need of nursing home care. See Watson, *supra* note 12, at 955-56.

⁷⁵ 42 U.S.C. § 1396d(a)(24), 1396d(a)(22).

⁷⁶ It prohibited payment for care in Institutions for Mental Diseases, which created incentives for states to move people from state-funded mental asylums to private nursing homes that were eligible for federally Medicaid matching funds. See TORREY, *supra* note 48, at 73.

⁷⁷ Watson, *supra* note 12, at 953.

⁷⁸ *Id.* at 952.

became the locus of care. It helped to dismantle public institutions but offered, for a period of time, an institutional alternative that continued to provide options for long-term care outside of the home. This institutional bias took the pressure off family caregivers and reduced their obligation, at least temporarily.

3. *Medicaid's Recent Shift: Care Returns Home*

Over the past few decades, however, Medicaid's institutional bias has receded, replaced by policies that aim to increase the autonomy of people with disabilities by helping them remain at home but, in turn, increase obligations for informal caregivers. Medicaid's evolving policies, have resituated the home as the locus of long-term care. This "rebalancing" has resulted in home- and community-based care increasing from eighteen percent of Medicaid's long-term care spending in 1995 to just over fifty percent in 2013.⁷⁹ More than three-quarters of people receiving long-term care assistance now live in home or community settings, which, in nearly all cases, means in their home or in the home of a family member.⁸⁰

Medicaid's shift to home-based long-term care has been largely motivated by care recipients' preferences to remain at home, which is why I describe it as policymaking from the care-recipient perspective. Early calls for home-based care came from the "independent living movement," an effort in the 1970s initiated by several working-age people with disabilities in Berkeley, to remain and live independently in their communities.⁸¹ Scandals regarding the deplorable conditions in private nursing homes and public institutions, coupled with concern over the growing costs of long-term care in these institutions, fanned the flames of the movement.⁸² Efforts were driven by the beliefs that outcomes are better and care is less expensive in home settings, but both of these beliefs are at best weakly substantiated empirically.⁸³

⁷⁹ Eiken et al., *supra* note 11, at 7 fig.1.

⁸⁰ NAT'L ALLIANCE FOR CAREGIVING & AARP, INC., CAREGIVING IN THE U.S.: 2009, at 8 (2009) [hereinafter NAT'L ALLIANCE, CAREGIVING], http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf ("Half of caregivers say their loved one lives in his or her own home (51%), while 29% live together with their care recipient. Only 4% of caregivers say that their care recipient lives in a nursing home and the same percentage say their recipient's home is an assisted living facility."); STONE 2008, *supra* note 70, at 3.

⁸¹ Batavia et al., *supra* note 48, at 528-29.

⁸² See Smith & Feng, *supra* note 28, at 32.

⁸³ See Avalere Health, *Medicaid-Financed Home and Community-Based Services Research: A Synthesis*, AM. HEALTH CARE ASS'N 5 (2007), https://www.ahcancal.org/research_data/funding/documents/hcbs_research_synthesis.pdf (reporting that home- and community-based services are not cost-effective for state budgets);

Deinstitutionalization litigation in the 1980s and 1990s challenged the conditions in and reliance on institutional care.⁸⁴ This litigation was supported by two very different groups: on the one hand, civil libertarians who wanted to end care in settings perceived to be “oppressive, dehumanizing, and antitherapeutic,” and, on the other, fiscal conservatives, who saw care at home as a way to cut spending.⁸⁵ They both aimed to unsettle institutions notorious for poor conditions and expensive care.

This litigation played out successfully in two waves. The first challenged the standards of treatment in public institutions on substantive due process grounds, relying on the assumption—one that proved true—that court orders requiring higher standards would make it too expensive for states to run these institutions.⁸⁶ The second wave relied on the then-recently passed Americans with Disabilities Act of 1990 (ADA) and its mandate to administer services “in the most integrated setting appropriate.”⁸⁷ The ADA enabled litigants, for the first time, to challenge conditions in publically-funded private institutions, including the private nursing home industry that Medicaid grew.⁸⁸ In 1999, the U.S. Supreme Court in *Olmstead v. L.C. ex rel. Zimring* held that institutionalization, when avoidable, can be a form of discrimination against people with disabilities.⁸⁹ States were required to make “reasonable modifications” to their Medicaid programs in response to *Olmstead*.⁹⁰

ANDREA WYSOCKI ET AL., LONG-TERM CARE FOR OLDER ADULTS: A REVIEW OF HOME AND COMMUNITY-BASED SERVICES VERSUS INSTITUTIONAL CARE 20-21 (2012), https://effectivehealthcare.ahrq.gov/ehc/products/369/1277/CER81_Long-Term-Care_FinalReport_20121023.pdf (surveying studies comparing nursing homes, assisted living, and HCBS programs and finding insufficient evidence on cost savings and most outcomes); David C. Grabowski, *The Cost-Effectiveness of Noninstitutional Long-Term Care Services: Review and Synthesis of the Most Recent Evidence*, 63 MED. CARE RES. & REV. 3, 20 (2006); Roger J. Stancliffe et al., *The Economics of Deinstitutionalization*, in COSTS AND OUTCOMES OF COMMUNITY SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITIES (Roger J. Stancliffe & K. Charlie Lakin eds., 2004) (showing the degree of cost savings as related to the degree of deinstitutionalization in a state).

84 See Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 CARDOZO L. REV. 1, 14 (2012).

85 *Id.* at 15.

86 *Id.* at 26. The Supreme Court’s 1982 decision in *Youngberg v. Romeo* held that institutionalized persons have “constitutionally protected interests in conditions of reasonable care and safety.” 457 U.S. 307, 324 (1982).

87 28 C.F.R. § 35.130(d) (2016).

88 Some deinstitutionalization advocates have even opposed care in multi-unit community-based settings and have attempted to label them “institutions” for purposes of *Olmstead* challenges. Bagenstos, *supra* note 84, at 48-49.

89 527 U.S. 581, 601 (1999) (reasoning that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment”).

90 See 28 C.F.R. § 35.130(b)(7) (2016). The exception is when modification would

It is telling that a number of family members of people with disabilities initially were part of the coalition but later splintered off because of concerns that the legal strategies pursued would unsettle institutions without offering alternatives,⁹¹ leaving them with unmanageable caregiving obligations. As they anticipated, the litigation created a tug of war for funding between institutions and programs for home- and community-based services. When enough people moved out of institutions, the fixed costs became too high to keep them open for individuals (or their guardians) who preferred institutional care, and a majority of public institutions closed.⁹²

In parallel to this litigation, Medicaid policies were increasingly making it easier for states to deinstitutionalize long-term care. Most importantly, Congress passed section 1915(c) of the Social Security Act in 1981, which allowed states to seek waiver approval to offer home- and community-based services instead of the institutional care that they otherwise were required to provide for all qualifying beneficiaries.⁹³ These waiver programs now operate in nearly all states and constitute two-thirds of Medicaid spending on home- and community-based services.⁹⁴

Policies that create incentives for states to shift to home- and community-based care continued in the subsequent decades. In 1991, the Department of Health and Human Services developed programs where states could offer Medicaid beneficiaries the ability to “self-direct” long-term care benefits,⁹⁵ which means they may pay any capable providers of services, including parents of children with disabilities and spouses.⁹⁶ The Deficit Reduction Act of 2005 and ACA created and extended a program called Money Follows the Person, which offers enhanced federal Medicaid matching funds to a state for twelve months after the state discharges an individual from institutional care

“fundamentally alter the nature of the service, program or activity.” *Id.*

91 Some parents pursued separate litigation to improve the conditions in institutions. DAVID J. ROTHMAN & SHEILA M. ROTHMAN, *THE WILLOWBROOK WARS* 45-50 (1984).

92 Bagenstos, *supra* note 84, at 7-9, 30; Stancliffe, et al., *supra* note 83, at 295.

93 *Medicaid Benefits*, CTRS. FOR MEDICARE & MEDICAID SERVS., <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Medicaid-Benefits.html> (last visited Aug. 15, 2016); *see also* STONE, *supra* note 69, at 9-10 (summarizing the 1915(c) home- and community-based services program). Waivers allow states to target services by age, diagnosis or geography, rather than having to be available statewide. *Id.* at 9.

94 TERENCE NG ET AL., KAISER COMM’N ON MEDICAID & UNINSURED, *MEDICAID HOME AND COMMUNITY-BASED SERVICE PROGRAMS: 2012 DATA UPDATE* 6-7 (2015), <http://files.kff.org/attachment/report-medicaid-home-and-community-based-services-programs-2012-data-update> (estimating 74 percent of funds on home- and community-based services are spent under 1915(c) waivers).

95 Jeffrey S. Crowley, *Medicaid Long-Term Services Reforms in the Deficit Reduction Act*, KAISER COMM’N ON MEDICAID & UNINSURED 15 (2006) (describing Section 1115 waivers for Cash and Counseling).

96 Benefits cannot be used to pay non-relative who owns or operates the facility or home in which the beneficiary lives, presumably to prevent moral hazard. *Id.*

to home care.⁹⁷ Nearly all states participate in this program, which, as of mid-2015, had prompted the transition of 50,000 individuals out of institutions and into home settings.⁹⁸ In effect, these two programs pay states a premium to move people out of institutions.

The result of this litigation and the policy reforms of the late twentieth century is that after several decades of momentum in the other direction, the law has quietly reaffirmed and solidified the home as the primary locale for long-term care. Federal policy began the large-scale dismantling of public institutions that states had established, a dismantling completed by civil rights litigation. In their place, Medicaid initially favored private institutions, but in recent years, this institutional bias has receded, replaced by favor for programs for home- and community-based services. The law has thus shifted long-term care back into the home and structurally reinforced its place there.

C. *The Resulting Structure of Long-Term Care*

Increasing reliance on home- and community-based services offers considerable benefits from a care-recipient perspective. It has freed many people from subpar conditions in facilities. People can stay in their homes and live as independently as possible, which can be transformative.⁹⁹ But the consequence of this reform has been to intensify and cement obligations for friends and family.

The number of people living in institutions has sharply declined. The census of people with developmental disabilities in state institutions is only sixteen percent of what it was at its peak in 1967, and the population of state and local psychiatric hospitals is nine percent of its peak and declining.¹⁰⁰ Age-adjusted institutional use among older Americans decreased by thirty-seven percent between 1984 and 2004.¹⁰¹ The actual number of older people

97 *Id.* at 9-11; *Medicaid Long-Term Services and Supports: Key Changes in the Health Reform Law*, HENRY J. KAISER FAMILY FOUND. 1 (2010), <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8079.pdf>. The Deficit Reduction Act also enabled states to expand eligibility for these services for higher earners without having to go through the waiver approval process. *Id.*

98 *Money Follows the Person: A 2015 State Survey of Transitions, Services, and Costs*, KAISER COMM'N ON MEDICAID & UNINSURED 1 (2013) (reporting over 50,000 transitioned and another 10,000 in progress).

99 See, e.g., Watson, *supra* note 12, at 937.

100 Bagenstos, *supra* note 84, at 29. The census of people with a developmental disability in state institutions peaked in 1967 at just under 200,000. *Id.* at 7. The census of people with psychiatric disabilities in state institutions peaked in 1955 at just under 560,000. *Id.* at 9.

101 DONALD L. REDFOOT & ARI HOUSER, AARP PUB. POL'Y INST., MORE OLDER PEOPLE WITH DISABILITIES LIVING IN THE COMMUNITY: TRENDS FROM THE NATIONAL LONG-TERM CARE SURVEY, 1984-2004, at 3 (2010), <http://assets.aarp.org/rgcenter/ppi/ltc/2010-08-disability.pdf> (using age-adjusted data based on the National Long-Term Care Survey).

living in institutions declined from a high of 2 million people in 1989 to 1.4 million in 2004, even as the absolute number of older Americans grew.¹⁰² By one estimate, if the rates of institutional use and disability had both remained constant, nearly 750,000 additional older people would have been living in institutions by 2004.¹⁰³ Likewise, by one estimate nearly 950,000 would have been in mental institutions in 2000; only 50,000 individuals were in 2003.¹⁰⁴ Medicaid spent \$24 billion less on nursing homes in 2004 than the program would have if institutionalization rates had remained constant from 1984.¹⁰⁵

What is more, there has been a substantial increase in the number of people with the very highest levels of disability living at home.¹⁰⁶ As one example, from 1999 to 2004, there was a twenty-four percent increase in the number of people living in home or community settings who need help toileting and a nearly twenty percent increase in the number who need mobility assistance.¹⁰⁷ The greatest increases occurred among the oldest old,¹⁰⁸ among widowed or unmarried people, especially women,¹⁰⁹ and among lower-income beneficiaries.¹¹⁰ This means that the number of poor, sick, old people living at home is increasing, due largely to Medicaid policies.

Importantly, funding for care in home settings has been insufficient. States have struggled to fund home- and community-based services.¹¹¹ The Medicaid waiver programs for these services must be budget neutral, or cost a state no more than what it would have spent to provide institutional care for the same beneficiaries. Yet, studies that compare a similar person in home versus institutional care suggest home-based care is not less expensive, as anticipated, due in part to scale disadvantages of care in smaller settings and also to the costs of developing networks of caregivers, crisis services, and case management.¹¹²

When a beneficiary is living in a nursing home, personal care needs are part of the total Medicaid-funded package. But when a beneficiary is living at

¹⁰² *Id.* at 21.

¹⁰³ *Id.* at 25 (based on institutional use in 2004).

¹⁰⁴ Bagenstos, *supra* note 84, at 9.

¹⁰⁵ REDFOOT & HOUSER, *supra* note 101, at 24.

¹⁰⁶ *Id.* at 25 (reporting that the share with disabilities in two or more ADLs increased from 57.5 to 69.5% from 1984 to 2004).

¹⁰⁷ *Id.* at 27.

¹⁰⁸ *Id.* at 28 (citing an 85% increase in people ages 85-94 and 240% increase in people over 95 years old with disability in two or more ADLs living in the community).

¹⁰⁹ *Id.* at 28 (citing an 81% increase for widowed people, as compared to a 39% increase for married people, and a 79% increase for women, as compared to a 45% increase for men, living with disabilities in multiple ADLs in the community).

¹¹⁰ *Id.* at 44 (three out of five older persons living in the community with disabilities in two or more ADLs report incomes less than \$20,000).

¹¹¹ NG ET AL., *supra* note 94, at 12-13.

¹¹² See studies cited *supra* note 82.

home, individual care needs can be and have been carved out. Unmet needs in nursing homes are more visible and reprehensible, but unmet needs in home settings are private and invisible to anyone other than close friends and family.

Most people in home- and community-based long-term care waiver programs have some unfunded care needs. To meet budget neutrality requirements, states have developed these programs with gaps—excluding some disabling conditions, limiting enrollment, or prohibiting aides or assistants from helping with some personal care activities, such as bathing or dressing.¹¹³ Moreover, in 2013 more than 536,000 people were on waiting lists for these programs with an average wait time of over two years.¹¹⁴ States also carve out and underfund personal care services for beneficiaries in the regular state programs. The few states that do pay for personal care limit it: for example, Utah and West Virginia allow only sixty hours of personal care per month, and Utah requires care be supervised by a registered nurse.¹¹⁵

To make matters worse, as part of a 1997 payment reform, Medicare reduced funding for post-acute home health care.¹¹⁶ In the three years following these changes, Medicare spending on home health fell from \$17.7 billion to \$8.5 billion, and the number of Medicare home health beneficiaries declined by 30 percent.¹¹⁷ Even though this funding was for medical care, never for personal assistance, its decrease has meant less nursing assistance and rehabilitative care in the home, so informal caregivers are now doing what medical professionals once did.

As a result of all of these policies, the average care recipient is experiencing a decline in formal paid care through social insurance programs, with the steepest decline in skilled care for those with more severe disabilities.¹¹⁸ For the lucky ones, family members or friends are stepping in to fill this gap in social insurance benefits. One study commented: “if patient care did not suffer as a result of reduced support from formal care sources, increased reliance on family caregivers is likely to have played an important

¹¹³ NG ET AL., *supra* note 94, at 12-14.

¹¹⁴ *Id.* at 3.

¹¹⁵ *Medicaid Benefits: Personal Care Services*, HENRY J. KAISER FAMILY FOUND. (2012), <http://kff.org/medicaid/state-indicator/personal-care-services>.

¹¹⁶ ARI HOUSER ET AL., AARP PUB. POL’Y INST., *TRENDS IN FAMILY CAREGIVING AND PAID HOME CARE FOR OLDER PEOPLE WITH DISABILITIES IN THE COMMUNITY: DATA FROM THE NATIONAL LONG-TERM CARE SURVEY 36* (2010), <http://assets.aarp.org/rgcenter/ppi/ltc/2010-09-caregiving.pdf>.

¹¹⁷ *Id.* (declining from 3.6 million to 2.5 million beneficiaries).

¹¹⁸ *Id.* at 32 (reporting a decline between 1999 and 2004 on the average hours of skilled care per individual with three or more ADL limitations).

role in minimizing adverse consequences.”¹¹⁹ In fact, nearly three-quarters of older people living in the community now receive family care only.¹²⁰ The work for the average informal caregiver has increased in level, complexity, and intensity.¹²¹

Modern long-term care policy has pivoted to better serve care recipients’ preferences and autonomy by financing care in home settings instead of in institutional ones. In concept, this shift is positive because it enables people with disabilities to live as they wish. But the laser focus on risk from the care-recipient perspective has overshadowed attention to competing risks, including those faced by family and friends.¹²² Under the auspices of serving the best interests of individuals with disabilities, the law has cemented and intensified responsibility for their friends and family—their next friends.

II. REIMAGINING LONG-TERM CARE RISK FROM THE NEXT-FRIEND PERSPECTIVE

What if we instead considered long-term care risk from the perspective of the closest friends and family of someone who is chronically ill or disabled? From this perspective, the possibility of becoming responsible for another’s long-term care can pose a major threat to an individual or family’s security and wellbeing.

Long-term care law and social policy has left gaping holes. Family and friends—“next friends”—have filled these gaps, most often by providing long-term care themselves, in part because in most cases no other good option exists. This tradition of long-term care as a private obligation is not new. But the world has changed in ways that make *de facto* reliance on friends and family increasingly untenable. Even if someone cares for another willingly, and even if she derives deep pleasure from it, she often does so at a high cost to herself. Whatever the friend or family member was engaged in before—be it paid employment, raising a family, getting an education, serving her community, nurturing a new relationship, or building a business—will be put on hold and possibly abandoned altogether. For many, this disruption takes a significant toll.

¹¹⁹ *Id.* at 36.

¹²⁰ *Id.* at 20.

¹²¹ NAT’L ALLIANCE, CAREGIVING, *supra* note 80, at 23 (noting that the “proportion of caregivers of adults who provide help with at least one ADL increased from 50% in 2004 to 58% in 2009”).

¹²² *Cf.* ULRICH BECK, RISK SOCIETY 31 (Mark Ritter trans., 1992) (describing how the emphasis on some risks can serve to overshadow others).

Legal scholarship has approached this problem in two ways. Health, elder, and disability law and policy scholars generally think of long-term care as an insurance problem. However, this literature treats care-recipient risk as the sole, or primary, insurable risk.¹²³ Some scholars acknowledge the burdens faced by informal caregivers and advocate for policies that offer better support, compensation, or more accommodating workplaces.¹²⁴ But even these scholars presume, explicitly or implicitly, continued reliance on family care in ways that ensconce it.

Second, there is a rich and complex literature by feminist legal scholars focused on caregiving. The main thrust of this work has been to highlight the undervaluation and gendered nature of care work, mostly with regard to childcare¹²⁵ and to a lesser extent long-term care.¹²⁶ Scholars in this tradition

123 See, e.g., Bagenstos, *supra* note 73; Karen Syma Czapanskiy, *Disabled Kids and Their Moms: Caregivers and Horizontal Equity*, 19 GEO. J. ON POVERTY L. & POL'Y 43 (2012) (analyzing the Department of Veterans Affairs' caregiver program in order to highlight the lack of public services that benefit caregivers of disabled children); Thomas P. Gallanis & Josephine Gittler, *Family Caregiving and the Law of Succession: A Proposal*, 45 U. MICH. J.L. REFORM 761 (2012) (proposing to amend succession law to provide an elective share to a family member who was a primary caregiver, providing unpaid informal care to an elderly decedent); Christopher C. Jennings & Christopher J. Dawe, *Long-Term Care: The Forgotten Health Care Challenge: Leading the Way to Broader Reform*, 17 STAN. L. & POL'Y REV. 57 (2006) (arguing for a private-public financing method for long-term care); Richard L. Kaplan, *Honoring Our Parents: Applying the Biblical Imperative the Context of Long-Term Care*, 21 NOTRE DAME J.L. ETHICS & PUB. POL'Y 483 (2007) (proposing that Medicare pay for all nursing home care and that any home care remain private responsibility); Marshall Kapp, *Home and Community-Based Long Term Services and Supports: Health Reform's Most Enduring Legacy?*, 8 ST. LOUIS U. J. HEALTH L. & POL'Y 9 (2014) (describing the shift to home- and community-based care); Daniela Kraiem, *Consumer Direction in Medicaid Long Term Care: Autonomy, Commodification of Family Labor, and Community Resilience*, 19 AM. U. J. GENDER SOC. POL'Y & L. 671 (2011) (critiquing consumer-directed long-term care programs for effects on paraprofessional and family care workers and arguing for better supports for caregivers); Watson, *supra* note 12 (providing a history of long-term care policy and a critique of Medicaid's institutional bias).

124 See, e.g., Czapanskiy, *supra* note 123, at 65-71 (proposing equity between state support for parents providing long-term care for children and the Department of Veterans Affairs' support for family caregivers); Gallanis & Gittler, *supra* note 123 (proposing to amend succession law to provide an elective share to a family member who was a primary caregiver); Richard L. Kaplan, *Federal Tax Policy and Family-Provided Care for Older Adults*, 25 VA. TAX REV. 509 (2005) (advocating for tax credits for family caregivers); Carol Levine, *Home Sweet Hospital: The Nature and Limits of Private Responsibilities for Home Health Care*, 11 J. HEALTH & AGING 341, 349-52 (1999) (proposing various supports for family caregivers, including more leave under the Family and Medical Leave Act, hospice funding, and home care benefits to supplement family care).

125 This body of work is larger than what I could possibly capture here. See, e.g., ALSTOTT, NO EXIT, *supra* note 22 (claiming that society owes an obligation to parents to help preserve their autonomy in exchange for the "no exit" obligation that they provide continuity of care for their children and make the sacrifices necessary to do so); MARTHA ALBERTSON

have made compelling arguments for state support of caregiving based on the idea of caregiving as a public responsibility,¹²⁷ a public good,¹²⁸ a basic household need,¹²⁹ or in order to help preserve women's attachment to the workplace.¹³⁰

This Article offers a reframing of the problem of long-term care that speaks to both groups. To the first, it suggests we consider next-friend risk a coequal, insurable risk of long-term care. Elucidating the possible economic and social harms a presumptive caregiver could face reveals a problem with the way that current policies steer some people into caregiving roles at the

FINEMAN, *THE AUTONOMY MYTH* 38 (2004) ("Justice demands that society recognize that caretaking labor produces a good for the larger society. Equality demands that this labor must not only be counted, but also valued, compensated, and accommodated by society and its institutions"); JOAN WILLIAMS, *UNBENDING GENDER: WHY FAMILY AND WORK CONFLICT AND WHAT TO DO ABOUT IT* (2000) (arguing for a joint-property proposal to value caregiving work in the home); Paula England & Nancy Folbre, *Who Should Pay for the Kids?*, 563 *ANNALS AM. ACAD. POL. & SOC. SCI.* 194 (1999) (contending that children are a public good and thus we should all help pay for the costs of raising them); Martha M. Ertman, *Commercializing Marriage: A Proposal for Valuing Women's Work Through Premarital Security Agreements*, 77 *TEX. L. REV.* 17 (arguing for premarital security agreements as a way of valuing women's domestic work and ensuring them compensation in the case of divorce); Sylvia A. Law, *Women, Work, Welfare, and the Preservation of Patriarchy*, 131 *U. PA. L. REV.* 1249 (1983) (showing that labor and welfare policy both prevent women from working outside the home and undervalue the work they do within it); Gillian Lester, *A Defense of Paid Family Leave*, 28 *HARV. J.L. & GENDER* 1 (2005) (defending paid leave as a way to increase women's workforce participation); Katherine B. Silbaugh, *Turning Labor into Love: Housework and the Law*, 91 *NW. U. L. REV.* 1 (1996) (showing how the law devalues domestic labor); Noah Zatz, *Supporting Workers by Accounting for Care*, 5 *HARV. L. & POL'Y REV.* 45 (2011) (arguing that we count childcare as part of the basket of goods for income-based programs and family caretaking as a form of work for benefits contingent on working).

126 Peggie Smith focuses explicitly on elder care, which she calls the "work-family issue of the 21st Century." Peggie Smith, *Elder Care, Gender, and Work: The Work-Family Issue of the 21st Century*, 25 *BERKELEY J. EMP. & LAB. L.* 351, 351 (2004) [hereinafter Smith, *Elder Care*]. Others address both childcare and long-term care together. See, e.g., FINEMAN, *supra* note 124 (describing all care work as the source of derivative dependency); Lester, *supra* note 124 (offering a normative argument for paid leave for childcare and eldercare); ALSTOTT, *NO EXIT*, *supra* note 22 (discussing caregiving for children with disabilities). Peggie Smith's work also examines long-term care from a labor perspective, showing how the devaluation of care work equally affects formal long-term caregivers. See Peggie Smith, *Home Sweet Home? Workplace Casualties of Consumer-Directed Home Care for the Elderly*, 21 *NOTRE DAME J.L. ETHICS & PUB. POL'Y* 537 (2007) [hereinafter Smith, *Home Sweet Home*]; Peggie Smith, *Aging and Caring in the Home: Regulating Paid Domesticity in the Twenty-First Century*, 92 *IOWA L. REV.* 1835 (2007). There is also a rich body of work on informal caregiving and long-term care by sociologists, historians, economists. E.g., EMILY ABEL, *WHO CARES FOR THE ELDERLY?* (1991); BORIS & KLEIN, *supra* note 31; HARTOG, *supra* note 29.

127 See ALSTOTT, *NO EXIT*, *supra* note 22.

128 See FINEMAN, *supra* note 125; England & Folbre, *supra* note 125.

129 See Zatz, *supra* note 125.

130 See Lester, *supra* note 125.

expense of other roles. Proposals to support informal caregivers privilege women's private caregiving at the expense of their long-term security and engagement in important realms outside of the home. Any solution to the problem must correct for this overvaluation.

To the feminist legal scholars, this Article offers a way of articulating the costs caregivers face as a manifestation of a coherent social risk and frames the state's responsibility in terms of risk spreading.¹³¹ Focusing on long-term care, instead of childcare more broadly, lends to this approach. The responsibility for someone else's long-term care is generally less predictable and more skewed in duration and intensity than typical childcare needs. Resulting costs fundamentally undermine caregivers' financial, emotional, and physical wellbeing.¹³²

Thinking about these costs in terms of social risk does not require someone to believe that care is a normative good or that society owes any obligation to people who do it well (even though a belief that these costs arise in service of doing something that we value can enhance a claim to shared resources). So long as enough people have experienced or worry about the possibility of becoming responsible for an aging parent, an ill spouse, or a child with a disability, they can relate to it as a commonly shared threat to security.

This Part examines what it would mean if, instead of deeming responsibility for long-term care as a private obligation, we treated the potential for becoming responsible for another as next-friend risk. Imagining next-friend risk could justify a fundamental change in how the state finances long-term care.

A. Long-Term Care as a Private Obligation

To conceive of a coherent idea of next-friend risk, it is necessary to identify who bears this risk and how it arises. These questions are complex because the obligation to care for someone is not inscribed in any one place, but rather is communicated through social norms and ethical beliefs, and sometimes through the law. The many sources that generate this obligation do not, however, diminish its veracity; quite the opposite, they mutually reinforce

¹³¹ Some scholars advocate for more circumscribed social insurance solutions, including Anne Alstott in the chapters of *No Exit* focused on parents caring for a child with disability and Gillian Lester with regard to paid leave to enable workers to take a leave for family care. ALSTOTT, *NO EXIT*, *supra* note 22; Lester, *supra* note 125. But none has intended to articulate a coherent theory of risk for all long-term caregivers nor to justify a comprehensive solution.

¹³² Anne Alstott argues that even more routine childcare can do the same. ALSTOTT, *NO EXIT*, *supra* note 22.

it, so that few people choose to walk away from a family member or friend in need of long-term care.

It is not always clear *ex ante* who will take responsibility for another's care. One expert writes: "Family responsibility is an amorphous concept, with fluid boundaries and interpretation. It may derive from religious teachings, cultural tradition, emotional bonds, gratitude for past acts, or a sense of obligation apart from love."¹³³ Regardless of why, the reality is that friends and family provide long-term care even at significant costs to themselves and even when not legally obligated to do so—prompting one scholar to call them "trapped kin."¹³⁴

1. *Social Norms and Long-Term Care*

Two different categories of arguments are proffered to explain why family members provide long-term care for each other. One view is that family care occurs because some people (usually women) have a "natural" inclination or a preference for caregiving. Thus, they and others are best off when they engage in caregiving, instead of other pursuits. In the past several decades, however, arguments in this vein have been challenged and discredited as tautological and often in service of certain political and economic goals.¹³⁵ Although many of us have a desire to care for those closest to us, explaining the decision that some people make to provide long-term care for others to be the result of rational choice or efficient specialization is unsatisfying, considering that in most cases it is the only option.

A second view is that norms—moral, religious, social, cultural, or legal—and institutions shape a strong notion of individual, typically gendered obligation to provide care.¹³⁶ This is the idea that obligation is constructed in part or whole. As Martha Fineman has described, "[C]hoice occurs within the constraints of social conditions, including history and tradition. Such

¹³³ Levine, *supra* note 124, at 344.

¹³⁴ HARTOG, *supra* note 29, at 278.

¹³⁵ See Rhonda J. Montgomery, *The Family Role in the Context of Long-Term Care*, 11 J. AGING & HEALTH 383, 395 (1999) (discussing studies that discredit this notion). Martha Fineman calls this argument "efficiency as exploitation." FINEMAN, *supra* note 125, at 44. One version of this idea is the human capital theory assertion that women have a comparative advantage for caregiving, which rationalizes their specialization in housework and men's in wage-earning work. Gary Becker argues, for example, that women's disadvantage in the workplace stems from specialization in childcare and housework, rather than discrimination. GARY BECKER, A TREATISE ON THE FAMILY 22 (1981). For a longer discussion of this use of human capital theory, its circularity, and studies that disprove it, see Vicki Schultz, *Life's Work*, 100 COLUM. L. REV. 1881, 1893 (2000).

¹³⁶ See, e.g., Amy Zietlow & Naomi Cahn, *The Honor Commandment: Law, Religion, and the Challenge of Elder Care*, 30 J.L. & RELIGION 229 (2015) (examining through qualitative empirical research how the Judeo-Christian "honor commandment" influences adult children's engagement in their parents' elder care).

traditions funnel individual decision making into prescribed channels, often operating along practical and symbolic lines to limit and close down options.”¹³⁷ She describes how everything from outdated historical traditions, to negative media attention on nannies or daycare, to the structure of the public school system with short school days and summer recesses create biases toward private caregiving.¹³⁸ Others have examined how sex discrimination in the workplace,¹³⁹ laws that do not tax the value of household labor,¹⁴⁰ and marriage and divorce laws¹⁴¹ all create incentives for women to choose caregiving for family over other work. Fully describing the social norms and institutions that shape such decisions is beyond the scope of this Article, but a few brief illustrations specific to long-term care illuminate how a sense of obligation might be communicated or reinforced.¹⁴²

As with childcare, women disproportionately provide long-term care. Gendered caregiving norms persist even though many women are less well-situated than many men for the physical labor of long-term care. Gendered expectations are shaped by families themselves: a “good” daughter, sister, or wife will care for her mother, brother, or husband.¹⁴³ That said, a significant and increasing number of men also provide long-term care.¹⁴⁴ The problem described herein is at the same time gendered and universal.

The purpose of family is even reduced, at times, to its role in long-term caregiving. The idea is that people have children in part to ensure someone to care for them when they get old,¹⁴⁵ a phenomenon one scholar describes as “an efficient self-insurance strategy adopted by families.”¹⁴⁶ To address the problem of elderly with unmet care needs, he even proposes taxing the aged

137 FINEMAN, *supra* note 125, at 41.

138 *Id.*

139 See Vicki Schultz, *Telling Stories About Women and Work: Judicial Interpretations of Sex Segregation in the Workplace in Title VII Cases Raising the Lack of Interest Argument*, 103 HARV. L. REV. 1749 (1990).

140 See Nancy C. Staudt, *Taxing Housework*, 84 GEO L.J. 1571, 1589 (1995).

141 See Anne L. Alstott, *Private Tragedies? Family Law as Social Insurance*, 4 HARV. L. & POL’Y REV. 3, 27 (2010); Vicki Schultz & Michael Yarbrough, *Will Marriage Make Gay and Lesbian Couples Less Egalitarian? A Cautionary Tale* (draft on file with author).

142 For a concise discussion of this idea, see Montgomery, *supra* note 135, at 384-90.

143 Historically, such requests were often accompanied by promises of property or another bequest. HARTOG, *supra* note 29, at 274-75.

144 See Jennifer L. Wolff & Judith D. Kasper, *Caregivers of Frail Elders: Updating a National Profile*, 46 GERONTOLOGIST 344, 348 (2006).

145 See generally HARTOG, *supra* note 29 (discussing the complex and changing relationship between increasingly aged parents and their children).

146 Douglas A. Wolf, *The Family as Provider of Long-Term Care: Efficiency, Equity, and Externalities*, 11 J. AGING & HEALTH 360, 368-69 (1999) (elaborating on a theoretical model developed by Mark Pauly).

without children for externalizing costs onto the public system and adopting measures to increase fertility, particularly in the case of childless families.¹⁴⁷

Medical practitioners often reinforce the concept of obligation to family care. One long-term care expert describes her experience after her husband became disabled in an accident, and a nurse foisted her husband's soiled pants on her, stating: "Take these away. Laundry is your job."¹⁴⁸ She also describes being labeled a "selfish wife" by a social worker, who was trying to discharge her husband from the hospital, for her refusal to take him home before she had established professional home care.¹⁴⁹ This view presumes that regardless of her work or other obligations her care for her husband should come first.¹⁵⁰

The law reinforces the norm of familial long-term care, in both implicit and explicit ways. The evolution of long-term care policy in Part I illustrates an implicit way that legal institutions rest on the expectations that friends and family will provide care. Medicaid long-term care benefits with gaps would be untenable if family and friends did not step in to fill these gaps. Sometimes obligations in the law are more explicit. For example, until recently, Medicare only covered hospice care if the beneficiary had a primary caregiver in place (typically a family member).¹⁵¹ For certified home health agencies, the availability of family care at home is still a chief consideration in opening a case to authorize Medicare-reimbursed home care.¹⁵²

Explicit legal obligations, even though largely dormant now, have helped shape expectations of private caregiving. All states have filial support laws, modeled on English Poor Laws of 1601, which create explicit obligations to pay for care for indigent family members.¹⁵³ Over half of the states' laws require adult children to care for or financially support indigent parents.¹⁵⁴ Although enforcement of these laws has waned since the New Deal's creation of a social safety net, they can nonetheless still shape social expectations, especially if periodically revived. Despite lying dormant for a while, filial support laws have been invoked again in recent years in several states,

¹⁴⁷ *Id.* at 373-74.

¹⁴⁸ Carol Levine, *The Loneliness of the Long-Term Caregiver*, 340 NEW ENG. J. MED. 1587, 1588 (1999). Such a statement is also a reflection of the historical conflict between providers of medical and non-medical care over status and role.

¹⁴⁹ *Id.*

¹⁵⁰ Research shows that medical professionals offer greater supports to male caregivers and express lower expectations for them to provide care directly. See Montgomery, *supra* note 135, at 392.

¹⁵¹ See Levine, *Home Sweet Hospital*, *supra* note 124, at 349.

¹⁵² See Levine, *supra* note 68, at 315-16.

¹⁵³ See Pearson, *supra* note 48, at 270; see also Sande L. Buhai, *Parental Support of Adult Children with Disabilities*, 91 MINN. L. REV. 710, 717-20 (2007) (describing the modern development of familial support obligations for disabled adult children and how these obligations in some ways resemble the original English Poor Laws).

¹⁵⁴ Pearson, *supra* note 48, at 278.

including in cases requiring adult children to reimburse a parent's medical¹⁵⁵ and nursing home expenses.¹⁵⁶ These laws might be revived more frequently as Baby Boomers impose higher costs on state Medicaid programs.¹⁵⁷ As late as the early twentieth century, many states passed laws that obligated parents to care for *adult* children with disabilities—in some cases only if the disability developed when the child was still a minor and, in others, even if a grown child became disabled later in life.¹⁵⁸

Common law has also defined the boundaries of family caregiving obligations. Historian Hendrik Hartog has documented the evolution of legal standards for elder care in the mid-nineteenth to twentieth century at a time when, as he describes, free market opportunities were seen as emancipating adult children from their parents.¹⁵⁹ During this period, as they aged, people used their estates, especially property, to bargain for care by family members, and “contract created or re-created the family as a corporate unit.”¹⁶⁰ What had once been outside of the zone of commodification—tending to a family member—became a bargaining chip for payment or property. Probate decisions at times deemed a potential beneficiary more deserving of inheritance if she fulfilled a promise to care for her aging parents.¹⁶¹ These cases defined the level of care that was expected from family by establishing what was above this level and could thus count as legally enforceable consideration.¹⁶²

Even in light of an overall trend of decreasing legal presumptions of obligation, important exceptions reflect lingering gendered expectations. For example, Hartog describes that litigation requesting fair compensation for care work required a showing of “exceptional” work; somehow the care work by men was usually perceived as more exceptional than that by women.¹⁶³ This idea that care is not exceptional (and thus requires no compensation) when done by women arises even in modern cases, such as the 1993 California case *Borelli v Brusseau*.¹⁶⁴ The court found a wife's agreement to provide intensive

¹⁵⁵ See *Savoy v. Savoy*, 641 A.2d 596, 600 (Pa. Supr. Ct. 1994); *Prairie Lakes Health Care Sys., Inc. v. Wookey*, 583 N.W.2d 405, 419 (S.D. 1998).

¹⁵⁶ See *Presbyterian Med. Ctr. v. Budd*, 832 A.2d 1066, 1077 (Pa. Super. Ct. 2003); *Health Care Retirement Corp. v. Pittas*, 46 A.3d 719, 724 (2012).

¹⁵⁷ See *Pearson*, *supra* note 48, at 302.

¹⁵⁸ See *Buhai*, *supra* note 153, at 716, 723, 730.

¹⁵⁹ HARTOG, *supra* note 29, at 21.

¹⁶⁰ *Id.* at 32.

¹⁶¹ *Id.*

¹⁶² *Id.* at 66.

¹⁶³ *Id.* at 257-58.

¹⁶⁴ 16 Cal. Rptr. 2d 16 (Ct. App. 1993). *But cf.* *O'Brien v. O'Brien*, 489 N.E.2d 712, 715-16 (N.Y. 1985) (recognizing the value of contributions made as a “spouse” and “homemaker” in a divorce action). Most modern cases go the way of *O'Brien*, not *Borelli*.

care for her disabled husband at home in return for a promise of part of his estate as without consideration.¹⁶⁵ As the dissent in *Borelli* argues (emphatically), this court's decision, relying on precedent from 1937 and 1941, was out of sync both doctrinally and with late twentieth-century social norms.¹⁶⁶ Nevertheless, it is an example of lingering articulation of the norm that women in kinship relationships are expected to provide long-term care and thus should neither expect nor receive anything, financial or otherwise, in return.

In one case, a California court ordered parents to pay \$3500 a month to a fifty-year old son who became disabled after nearly two decades of work as a lawyer.¹⁶⁷ In an attempt to ensure that poor people with disabilities get needed care, and also that they do not become a public expense, the law has expressly obligated family members to serve as caregivers.

Gendered notions of familial obligation surface explicitly at times in policymaking as well, leaving little to the imagination in terms of what drives policy decisions. In congressional hearings on home health care, Representative Tom Coburn suggested that paid care is inappropriate when a family member could provide it. He attempted to illustrate the inefficiency of government-funded home care by criticizing the fact that a diabetic patient was using publicly financed caregivers despite the fact that his "wife was a nurse, trained to measure sugars and give injections."¹⁶⁸ Coburn's presumption was that the wife should take on the role of his caregiver, nursing her husband, rather than others, as her job.

What is clear is that these various expressions of social expectations for family care, even if waning somewhat in recent years, can influence the way people respond when a family member or friend is in need of long-term care. Sociologist Sandra Levitsky found that among unpaid family caregivers, most discussed their own circumstances—even when precarious—in "legitimizing" terms as their responsibility and duty.¹⁶⁹ Most informal caregivers struggled to imagine a state role in long-term care, unless they had personally observed

¹⁶⁵ *Borelli*, 16 Cal. Rptr. 2d at 17, 20 ("Personal performance of a personal duty created by the contract of marriage does not constitute a new consideration supporting the indebtedness alleged in this case.")

¹⁶⁶ *Id.* at 22 (Poché, J., dissenting).

¹⁶⁷ See Petition to Enforce Parental Duty to Support Adult Indigent Child, *Culp v. Culp*, D279304 (Ventura Super. Ct. Dec. 29, 2000).

¹⁶⁸ DEBORAH STONE, RADCLIFFE PUB. POL'Y CTR., REFRAMING HOME HEALTH-CARE POLICY 21 (2000), <https://policyparadox.files.wordpress.com/2014/10/reframing-home-health-2000.pdf> (citing *Medicare Home Health Care, Skilled Nursing Facility, and Other Postacute Care Payment Policies: Hearing Before H. Comm. on Ways & Means, Subcomm. on Health*, 105th Congress 24).

¹⁶⁹ Sandra R. Levitsky, *What Rights? The Construction of Political Claims to American Health Care Entitlements*, 42 L. & SOC'Y REV. 551, 564 (2008).

how Medicaid could cushion the burden of caregiving.¹⁷⁰ The bottom line is that a complex set of social and legal norms have shaped expectations that family and friends, especially women, will provide long-term care.

2. *The Numbers on Informal Caregiving*

The manifestation of a sense of private obligation is readily evident in the number of people who take on responsibility for the long-term care of another and the intensity of the care they provide. By one estimate, over forty million people provided some unpaid assistance to someone with functional or cognitive limitations in 2013.¹⁷¹ One study of Baby Boomers caring for their parents found that the percentage of people providing basic personal care to parents more than tripled between 1994 and 2008.¹⁷² Most informal caregivers care for family, primarily for parents but also for grandparents, siblings, spouses, and children.¹⁷³ Yet, estimates suggest that as many as one-fifth of informal caregivers provide care for a non-relative, including eleven percent for a friend,¹⁷⁴ illustrating how obligation reaches beyond narrow definitions of family.

Two-thirds of informal caregivers are women.¹⁷⁵ Gendered differences exist beneath the surface as well. For example, when compared to sons caring for parents, daughters tend to provide more hours of care, engage in more care tasks, and more often live with the parent.¹⁷⁶ Furthermore, as care needs intensify, daughters more often continue caregiving than sons, who hire out care.¹⁷⁷ The average age of an informal caregiver is forty-eight years old.¹⁷⁸ This means that the burden of providing informal long-term care especially

¹⁷⁰ See *id.* at 578-79.

¹⁷¹ Reinhard et al., *supra* note 26, at 1 (2011).

¹⁷² METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 7.

¹⁷³ See NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 18 (reporting that 86% of survey respondents reported caring for family, including 36% for parents, 14% for children, 8% for parents-in-law, 8% for grandparents, 5% for a spouse or partner, and 5% for a sibling); Karen Donelan et al., *Challenged to Care: Informal Caregivers in a Changing Health System*, 21 HEALTH AFF. 222, 224 (2002) (reporting that 79% of survey respondents providing informal care said they cared for family: 42% for parents, 17% for grandparents, 7% for siblings, and 6% for children).

¹⁷⁴ See NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 18; Donelan et al., *supra* note 173, at 224.

¹⁷⁵ NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 14.

¹⁷⁶ Rhonda Montgomery et al., *Family Caregiving*, in HANDBOOK OF GERONTOLOGY: EVIDENCE-BASED APPROACHES TO THEORY, PRACTICE AND POLICY (James A. Blackburn & Catherine N. Dulmus eds., 2007).

¹⁷⁷ See NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 17.

¹⁷⁸ *Id.*

affects women during years that are critical for careers and, increasingly, for raising children as the average maternal age rises.¹⁷⁹

Differences in rates of long-term caregiving exist also across race and income, although they are not as stark. The prevalence of informal caregiving is highest in Hispanic and African-American households and lowest in Asian-American ones, in part driven by disparate levels of need.¹⁸⁰ Informal caregivers are disproportionately low-income: one study estimates 44 percent of working age caregivers are in households below 200 percent of the federal poverty level, as compared with 33 percent of non-caregivers.¹⁸¹

The variation in informal caregiving is significant, measured both in duration and in intensity of care. On average, the duration of caregiving is 4.6 years, skewed upward by the 3 in 10 caregivers who provide care for five years or more.¹⁸² The average caregiver provides just over twenty hours of care per week, but thirteen percent of people provide forty hours or more of care per week.¹⁸³ Over fifty percent of informal caregivers provide assistance with at least one activity of daily living, most often transferring or getting dressed, and all with at least one instrumental activity of daily living, such as housework, grocery shopping, or preparing meals.¹⁸⁴

Changes in medicine and medical reimbursement have increased the intensity of informal care.¹⁸⁵ Medicare reform in 1983 reduced payment for care in hospital settings, leading to what is often called “quicker and sicker” discharge.¹⁸⁶ Sociologist Cameron Macdonald calls these policies “healthcare

179 See JOYCE A. MARTIN ET AL., BIRTHS: FINAL DATA FOR 2009, NATIONAL VITAL STATISTICS REPORTS 6 fig. 4 (2011), http://www.cdc.gov/nchs/data/nvsr/nvsr60/nvsr60_01.pdf.

180 See NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 12 (reporting a prevalence of caregiving of 36.1% of Hispanic, 33.6% of African-American, 30.5% of White, and 20.0% of Asian-American households); Alice Ho et al., *A Look at Working-Age Caregivers' Roles, Health Concerns, and Need for Support*, COMMONWEALTH FUND 7 (2005), http://www.commonwealthfund.org/~media/files/publications/issue-brief/2005/aug/a-look-at-working-age-caregivers-roles--health-concerns--and-need-for-support/854_ho_lookatworkingcaregiversroles_ib-pdf.pdf.

181 Ho et al., *supra* note 180, at 2. Of course, these households might be lower income because of caregiving obligations.

182 NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 19.

183 *Id.* at 21.

184 *Id.* at 22-24. Those caring for children help with most Childcare Support Activities (CSAs). *Id.* at 27.

185 See generally Sara M. Moorman & Cameron Macdonald, *Medically Complex Care and Caregiver Strain: Results from the Cash and Counseling Demonstration and Evaluation Study*, 53 GERONTOLOGIST 417 (2012) (describing the increase of medicalization of home care and its effects on family caregivers).

186 REDFOOT & HOUSER, *supra* note 101, at 8 (describing the creation of the Medicare Prospective Payment system to reimburse a fixed amount for an episode of care, resulting in shorter hospital stays).

offloading” because of the way that they shift the burden of care from medical institutions to families.¹⁸⁷

As a result, informal caregivers report providing higher-intensity levels of care.¹⁸⁸ One study found that over forty percent of informal caregivers were performing at least one medical task, including wound care, intravenous medication, and operating dialysis and home infusion machines.¹⁸⁹ Some of the equipment involved is complex, including connecting ventilators to tracheostomy sites, responding to alarms and failures, programming feeding tubes and monitoring for blockages or signs of infection, and noting medical complications quickly, including signs of pneumonia.¹⁹⁰ Most informal caregivers have little or no training and provide care in a home setting with no help from paid aides, housekeepers, or others.¹⁹¹ One-quarter said they were performing medical tasks because their care recipient had been sent home “too soon,” and one in eight reported being aware of a mistake they had made in medical management, showing that this higher-intensity care puts family caregivers in a vulnerable position where they may make errors that harm a loved one.¹⁹² Not surprisingly, the negative health, financial, social, and professional impact is greater among caregivers who assist in health care activities.¹⁹³

As one informal caregiver and scholar described: “I feel abandoned by a health care system that commits resources and rewards to rescuing the injured and the ill but then consigns such patients and their families to the black hole of chronic ‘custodial’ care.”¹⁹⁴ What next friends do for others is herculean, both in terms of the time spent and the ways that they offer assistance.

B. Obligation in a Changing World

The world has changed in ways that make this type of intense, private obligation untenable. Long-term care needs are growing with the shifting demographics of the population. Medical advances are keeping people alive longer and sicker. In 2009, the life expectancy at birth for an American was nearly seventy-nine years, ten years longer than it was in the mid-twentieth

187 Cameron Macdonald, *Is There A Doctor in the House?: Family Members Providing Complex Medical Care at Home* (unpublished manuscript) (on file with author).

188 Donelan et al., *supra* note 173, at 224.

189 *Id.* at 225-226.

190 See Moorman & Macdonald, *supra* note 185, at 408.

191 See NAT’L ALLIANCE, *CAREGIVING*, *supra* note 80, at 32, 59.

192 Donelan et. al., *supra* note 173, at 226-27.

193 See Jennifer L. Wolff et al., *A National Profile of Family and Unpaid Caregivers Who Assist Older Adults with Health Care Activities*, 176 JAMA INTERNAL MED. 372 (2016)

194 Levine, *supra* note 148, at 1588.

century and twenty years longer than the beginning of the twentieth century.¹⁹⁵ Heroic trauma care and miracle drugs are preserving and extending lives of people with serious injury.¹⁹⁶ And the number of “old old” is growing as a percentage of the population.¹⁹⁷ More Americans suffer from chronic disease than ever before, and some studies suggest the proportion of Americans with chronic conditions may continue to rise.¹⁹⁸ Plus, rates of childhood disability have increased as much as sixteen percent from 2001 to 2010.¹⁹⁹

As the Baby Boomers transition from the caregiving to the care-receiving generation, the probability of caring for an aging family member or friend is increasing. The ratio of people in need of care to potential caregivers is increasing as people live longer and have fewer kids, translating into a higher likelihood that any one individual will become responsible for another.²⁰⁰

At the same time, family and community are evolving in ways that destabilize the provision of informal caregiving in households. A higher percentage of women are in the labor force than ever before: from one-third in 1950 to nearly two-thirds at the beginning of the twenty-first century.²⁰¹ The frequency of single-parent households has also risen, from twenty percent in 1980²⁰² to thirty-four percent in 2011.²⁰³ And for households where there is a married couple, the percentage in which both spouses work out of the home

195 See Elizabeth Arias, *United States Life Tables, 2009*, NAT'L VITAL STAT. REP., Jan. 6, 2014, at 2, 52-53 tbl.21, http://www.cdc.gov/nchs/data/nvsr/nvsr62/nvsr62_07.pdf.

196 See Batavia et al., *supra* note 48, at 523 (citing studies about the changing nature of disability).

197 Arias, *supra* note 195, at 47.

198 Gerard Anderson & Jane Horvath, *The Growing Burden of Chronic Disease in America*, 119 PUB. HEALTH REP. 263, 267 (2004) (reporting that 125 million Americans, or 45% of the population, had one or more chronic health conditions in 2000 and projecting an increase over the next 30 years (citing to a confidential client memorandum from Rand Corporation that was created for Johns Hopkins)). Research reported the proportion of informal caregivers caring for someone with Alzheimer's or dementia rose from 6 to 12 percent from 2004 to 2009. NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 41.

199 *Childhood Disability Rate Jumps 16% over Past Decade*, AM. ACADEMY PEDIATRICS, (May 5, 2013), <http://www.aap.org/en-us/about-the-aap/aap-press-room/Pages/Childhood-Disability-Rate-Jumps.aspx>.

200 See Brandon, *supra* note 16 (reporting that the proportion of Americans aged 65 and older has grown from 4.1% in 1900 to 13% in 2012).

201 Fullerton, Jr., *supra* note 14, at 4 tbl.1.

202 U.S. CENSUS BUREAU, *supra* note 14, at 840 tbl. 1337.

203 U.S. CENSUS BUREAU, AMERICA'S FAMILIES AND LIVING ARRANGEMENTS: 2011, tbls. FG6, F1, <http://www.census.gov/population/www/socdemo/hh-fam/cps2011.html> (calculated by dividing total number of one-parent households living with their own children under age 18 in table FG6, 11,759, by total number of households with parents living with their own children in F1).

increased from just over forty-four percent in 1967 to sixty percent at the beginning of the twenty-first century.²⁰⁴

At one time, people lived in communities where they could share care obligations, but people are leaving their communities more often than before. In 2010, 41 percent of Americans lived outside the state in which they were born, as compared to 26.5 percent in 1950.²⁰⁵ Sixty-three percent of adults have moved to a new community at least once in their lives, while only thirty-seven percent have never left their hometowns.²⁰⁶

All of these changes make the burdens that have been shouldered privately increasingly untenable for many, exposing long-term caregiving because it no longer folds quietly into the familial fabric. The combination of law and policies that move care back into the home, in addition to the changing home environments, has resulted in costs too significant to ignore.

C. *The Cost of Private Obligation: The Invisible Copayment*

When someone becomes responsible for another's long-term care, the burdens can be high.²⁰⁷ Some of these burdens can be quantified in monetary terms. Others, even if not easily measurable financially, are no less harmful, including damage to intimate relationships or health and an inability to pursue life goals. These costs are, in effect, the invisible copayment of current long-term care social insurance programs.

It is normatively and empirically difficult to put a value on the invisible copayment.²⁰⁸ As noted above one conservative estimate of replacement wages for the hours of informal caregiving for adults in 2013, when valued at

204 U.S. BUREAU OF LABOR STATISTICS, WOMEN IN THE LABOR FORCE: A DATABOOK 84-85 tbl. 24 (2014). A married-couple household is defined as a husband and wife, with or without children, who maintain their own household. *Id.* The number of dual-earner families decreased in the last years of collected data (2009-2011), during the recession. *Id.*

205 Ren, *supra* note 15, at 4.

206 PAUL TAYLOR ET AL., PEW RESEARCH CTR., AMERICAN MOBILITY: WHO MOVES? WHO STAYS PUT? WHERE'S HOME? 1-2 (2008), <http://pewsocialtrends.org/files/2011/04/American-Mobility-Report-updated-12-29-08.pdf>.

207 How one defines "burdens," "harm," or "costs" greatly shapes the content of what is considered risk. For the moment, I intentionally discuss cost broadly, in both monetary and nonmonetary terms, in terms of lost income and lost opportunity. In Part III, I address different ways people might define harm and how that would affect someone's definition of next-friend risk.

208 As explained in Part III *infra*, the metrics used to estimate this value implicitly express how we define the harm, in terms of time and money spent or opportunity or autonomy lost. In this Article, I am taking a relatively agnostic approach to this question, because with any approach, the costs would be extremely high and lend support to the position that next-friend risk is worthy of greater attention.

average caregiving wages of \$12.51 per hour, is \$470 billion.²⁰⁹ Other estimates that measure that costs instead as opportunity costs to informal caregivers are similar in magnitude.²¹⁰ For a subset of informal caregivers, who leave or reduce work to provide care, the total financial losses can be staggering. The average informal caregiver who leaves the workforce to care for a parent faces losses including foregone income, pensions, earned interest, benefits, and retirement benefits, including Social Security. One study estimates these losses to be \$300,000, on average, and others estimate them to be as high as \$600,000 for some caregivers.²¹¹ For someone caring for a parent who reduces working hours but does not leave a job, studies estimate average losses still near \$200,000.²¹² Among all informal caregivers twenty percent take a leave of absence.²¹³ More than one-third of those caring for their parents leave the workforce or reduce working hours.²¹⁴ Considering that the median household net worth was just under \$70,000 in 2011,²¹⁵ losses at this level are devastating for all but the wealthiest households. An estimate of the aggregate costs of Baby Boomers caring for their parents, measured in lost wages, Social Security, and pension, is nearly \$3 trillion dollars.²¹⁶ Not surprisingly, one-third of caregivers report moderate to high financial hardship due to caregiving.²¹⁷

Because of its gendered nature, informal caregiving contributes to wage and employment gaps.²¹⁸ Women are more likely than men to disrupt or leave work for caregiving.²¹⁹ Evidence shows that extended periods of leave from

²⁰⁹ See sources cited *supra* note 26.

²¹⁰ See, e.g., Chari et al, *supra* note 26, at 877 (estimating opportunity costs of elder care to be \$522 billion annually).

²¹¹ METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 15 (estimating average losses of \$283,716 for men and \$324,044 for women among Baby Boomers caring for their parents); METLIFE MATURE MKT. INST., THE METLIFE JUGGLING ACT STUDY: BALANCING CAREGIVING WITH WORK AND THE COSTS INVOLVED 5-6 (1999), <http://www.caregiving.org/data/jugglingstudy.pdf> (reporting an average wage loss of \$566,443, with a median wage loss of \$243,761; the study also found an average Social Security loss of \$25,494 and pension loss of \$67,202), see also Skira, *supra* note 18, at 82 (estimating a median loss of \$164,726 over two years).

²¹² METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 14.

²¹³ NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 9.

²¹⁴ METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 10.

²¹⁵ U.S. CENSUS BUREAU, NET WORTH AND ASSET OWNERSHIP OF HOUSEHOLDS: 2011, <http://www.census.gov/people/wealth>.

²¹⁶ METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 15.

²¹⁷ NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 51.

²¹⁸ Skira, *supra* note 18, at 63-64, 79.

²¹⁹ METLIFE, DOUBLE JEOPARDY, *supra* note 18, at 10; see also U.S. DEPT. OF LABOR, FMLA SURVEY: BALANCING THE NEEDS OF FAMILY AND EMPLOYERS tbl. A2-2.6 (2001) (reporting that 32.2% of women who took leave from work in 2000 used it to care for an adult or child (excluding newborns), as compared to 28.9% of men who took leave).

work significantly hamper professional advancement.²²⁰ Even those who stay in the workplace are unlikely to be able to perform as strongly as those not providing long-term care. Long-term caregivers are twice as likely to miss six or more days of work than non-caregivers.²²¹ By one estimate, U.S. businesses experience nearly \$30 billion a year in lost productivity from full-time employees who are caring for family because of absenteeism, distraction, and reduced hours.²²² Employers pay about eight percent more for health care for employees who care for an older person, totaling over \$13 billion per year.²²³ Employers are, in turn, less likely to invest in employees who provide long-term care.²²⁴

Informal caregiving can contribute to a cycle of poverty, especially since informal caregivers are more likely to be in low-income households.²²⁵ Political scientist Joe White describes: “Reliance on intra-family transfers carries the same risks as personal investments, especially since individuals with low incomes tend to have children with low incomes, and so a parent’s misfortune would be doubly visited upon his or her children.”²²⁶ To the extent someone depletes her resources or forgoes savings and retirement benefits to care for another, she will be less likely to be able to afford care for herself later if needed. Thus, family caregiving can solidify class lines as each generation sacrifices its financial security for another one.

Quantifying harm only in terms of hours of unpaid care or lost income, however, does not begin to capture the impact of informal caregiving on people’s lives. A considerable body of research measures “secondary strains,”

220 See, e.g., Joyce P. Jacobsen & Laurence M. Levin, *Effect of Intermittent Labor Force Attachment on Women’s Earnings*, MONTHLY LABOR REV., Sept. 1995, at 14, 18 (“Even women whose labor force gap occurred more than 20 years ago still earn between 5 percent and 7 percent less than women who never left the labor force and have comparable levels of experience . . .”).

221 Ho et al., *supra* note 181, at 3.

222 REINHARD ET. AL., *supra* note 26, at 7.

223 NAT’L ALLIANCE FOR CAREGIVING ET AL., THE METLIFE STUDY OF WORKING CAREGIVERS AND EMPLOYER HEALTH CARE COSTS: NEW INSIGHTS AND INNOVATIONS FOR REDUCING HEALTH CARE COSTS FOR EMPLOYERS 4 (2010), <https://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-working-caregivers-employers-health-care-costs.pdf> (using a conservative estimate).

224 See Anne Beeson Royalty, *The Effects of Job Turnover on the Training of Men and Women*, 49 INDUS. & LABOR REL. REV. 506, 520 (1996) (stating that employers are 25% more likely to provide training to men than women due to the assumption that women will leave the workforce for family reasons).

225 Yeonjung Lee et al., *The Vicious Cycle of Parental Caregiving and Financial Well-being: A Longitudinal Study of Women*, 70 J. GERONTOLOGY SERIES B: PSYCHOL. SCI. & SOC. SCI. 425, 426 (2015).

226 Joseph White, *(How) Is Aging a Health Policy Problem?*, 4 YALE J. HEALTH POL’Y L. & ETHICS 47, 56 (2004).

including effects on “family and occupational role and social and recreational activities, and intrapsychic strains such as loss of self-esteem, loss of self, role captivity, and lowered sense of competence.”²²⁷ This research documents significant health effects and psychosocial and behavioral impacts. The self-reported health of informal caregivers is worse than that of non-caregivers, and it declines the longer someone provides care.²²⁸ In one study, over two-thirds of respondents reported that long-term caregiving was the top source of stress in their lives.²²⁹ Research has shown that forty to seventy percent of people caring for older adults have symptoms of depression and twenty-five to fifty percent meet diagnostic criteria for major depression, far outpacing the rates in the general population.²³⁰ Significantly, health status is worse for an informal caregiver who felt she had no choice in whether to provide care.²³¹

Even beyond measurable physical and psychosocial harms, taking responsibility for the long-term care of another, especially for someone who requires prolonged intensive care, can consume life in ways difficult to quantify but nonetheless important. Long-term care responsibility can harm existing relationships or create barriers to entering into new intimate relationships. Anne Alstott has argued that social policy should be just as concerned about a wider range of risks that can threaten wellbeing and security, which she refers to as disruptions in “affective life.”²³² In one study, one-half of caregivers reported sacrificed time with friends and family.²³³

An informal caregiver could lose the chance to engage in other activities that define her, fulfill her, or create future opportunity for her. Both because of the economic insecurity it can create and equally because of the way it can absorb a great proportion of someone’s time and mental space, responsibility for another’s long-term care can impede pursuit of one’s life goals—what some call self-determination, self-actualization,²³⁴ or engagement in “the life

227 Montgomery et al., *supra* note 176, at 6.

228 NAT’L ALLIANCE, CAREGIVING, *supra* note 80, at 47. One-third of caregivers report moderate to high physical strain. *Id.* at 49. Three-fifths report at least one chronic condition, as compared with one-third of non-caregivers. Ho et al., *supra* note 181, at 2.

229 Lynn Feinberg et al., *Valuing the Invaluable: 2011 Update—The Growing Contributions and Costs of Family Caregiving*, AARP PUB. POL’Y INST., 7 (2011), <https://assets.aarp.org/rgcenter/ppi/lc/i51-caregiving.pdf>.

230 Steven H. Zarit, *Assessment of Family Caregivers: A Research Perspective*, in 2 CAREGIVER ASSESSMENT: VOICES AND VIEWS FROM THE FIELD: REPORT FROM A NATIONAL CONSENSUS DEVELOPMENT CONFERENCE 12, 14 (Family Caregiver Alliance ed., 2006).

231 NAT’L ALLIANCE, CAREGIVING, *supra* note 80, at 20-21, 50 (43 percent of caregivers report feeling this way, half of whom serve as a primary caregiver).

232 Alstott, *supra* note 141, at 5.

233 NAT’L ALLIANCE, CAREGIVING, *supra* note 80, at 50-51.

234 Self-actualization is the highest level of Maslow’s hierarchy of needs. See Abraham H. Maslow, *A Theory of Human Motivation*, 50 PSYCH. REV. 370, 382 (1943) (“[Self-actualization] refers to the desire for self-fulfillment, namely, to the tendency for him to become actualized in what he is potentially. This tendency might be phrased as the desire to become

of a civilized being.”²³⁵ Although more difficult to measure, these harms are nonetheless devastating.

In sum, even if people take on caring for another with great generosity and love, long-term care is extremely demanding. Even in the best of circumstances, it will take a toll.

D. Reimagining Private Obligation as Social Risk

What if we reimagine these costs as the result of next-friend risk, rather than an individual obligation? Long-term care clearly undermines the security of modern American families and can be understood as a source of risk for next friends.

What does it mean for something to be a “risk”? Technical definitions describe risk in actuarial terms as a probabilistic harm from a particular hazard.²³⁶ Next-friend risk clearly fits this conception. Most of us *could* end up responsible for the long-term care for another, even if not all of us *will*. The costs that result are stochastic, skewed, and, in the worst cases, devastating.²³⁷ Responsibility is only triggered when illness or injury affects a family member or friend, rarely due to the fault of a next friend, as examined in more detail below. Even if someone finds providing long-term care for a loved one rewarding, it is not a role that most people anticipate and embrace.²³⁸ Taking an *ex ante*, collective view, the possibility of responsibility for the long-term care of another shares many attributes with other phenomena that we have treated as serious social risks—from workplace injury to the potential of poverty in old age from outliving one’s savings.

Yet not all probabilistic harms are considered and treated as salient social risks. Sociocultural risk scholars examine how what a society defines as risk is

more and more what one is, to become everything that one is capable of becoming.”).

235 T.H. MARSHALL. CITIZENSHIP AND SOCIAL CLASS: AND OTHER ESSAYS 11 (1950).

236 *E.g.*, FRANK KNIGHT, RISK, UNCERTAINTY, AND PROFIT 19-20, 224-25, 231-32 (1921) (defining risk as quantitative and anything “non-quantitative,” in contrast, as “uncertainty”); *see also* Nick J. Fox, *Postmodern Reflections on ‘Risk’, ‘Hazards’ and Life Choices*, in RISK AND SOCIOCULTURAL THEORY: NEW DIRECTIONS AND PERSPECTIVES (Deborah Lupton ed., 1999) (describing how risk can mean the potential for significant loss or reward but is more often thoughts about in terms of loss).

237 Even though next-friend risk is random to the extent it is impossible to know whether and when a friend or family member will become ill or disabled, some characteristics nevertheless increase any one individual’s chance of experiencing it by making them more likely to be responsible for others, such as being a member of a small family or being a woman. Other characteristics, such as being part of a middle-class family might decrease next-friend risk. Cameron Macdonald has shown that middle class families more often live in communities with extended support networks, decreasing any one person’s likely burdens. Macdonald, *supra* note 187.

238 *See* Lester, *supra* note 125, at 12, 15.

socially mediated.²³⁹ French historian and philosopher François Ewald takes an especially relativist stance: “anything *can* be a risk; it all depends on how one analyzes the danger, considers the event.”²⁴⁰ Unlike Ewald, most scholars in this tradition believe that some measurable danger underlies what we see as risk.²⁴¹ In other words, risk is both objective and socially mediated. This way of defining risk explains why even if a hazard is not presently thought of as a social risk, it does not mean it could and should not be. Calling a phenomenon “risk” signals two things: that it causes probabilistic harm and also that it is salient as such.

Certain harms have greater salience as risky, based on how they are framed, by whom, and with what agenda in mind. Sociologist Ulrich Beck describes an “overproduction of risks,” when interested parties magnify some risks in order to, in turn, diminish concomitant risks. As an example, he explains that “the dramatization of climactic consequences ‘minimizes’ the risk of nuclear energy.”²⁴² This practice is pervasive. The risk from overly aggressive (and perhaps unscrupulous or criminal) banking practices is tolerated in light of claims that certain financial institutions are “too big to fail.”²⁴³ In *Mutual Pharmaceutical Co. v. Bartlett*, a lawsuit claiming serious injury from a generic anti-inflammatory drug, the pharmaceutical company’s lawyers highlighted the harm of rising health care costs due to brand-name drugs in order to suggest that the low risk that a generic drug would cause someone’s skin to burn and slough off, as it did to Karen Bartlett, was not unreasonably dangerous.²⁴⁴ A web of interested parties and complex dynamics shape the collective concern with certain risks and not with others.²⁴⁵

²³⁹ See, e.g., BECK, *supra* note 122, at 21 (“Risk may be defined as a *systemic way of dealing with hazards and insecurities introduced by modernization itself*.”); MARY DOUGLAS & AARON WILDAVSKY, *RISK AND CULTURE* (1982) (proposing a cultural theory of risk); Mitchell Dean, *Risk, Calculable and Incalculable*, in *RISK AND SOCIOCULTURAL THEORY*, *supra* note 236, at 131; François Ewald, *Insurance and Risk*, in *THE FOUCAULT EFFECT* 197 (Graham Burchell et al. eds., 1991); Ewald, *supra* note 24; Steve Rayner, *Cultural Theory and Risk Analysis*, in *SOCIAL THEORIES OF RISK* (Sheldon Krinsky & Dominic Golding eds. 1992); see also BAKER & SIMON, *supra* note 23; DEBORAH LUPTON, *RISK* (1999) (providing an overview of different schools of sociocultural risk scholarship). Social typically is used to refer to society at large and cultural to sub-groups within it.

²⁴⁰ Ewald, *supra* note 239, at 199.

²⁴¹ See Nick Fox, *Postmodern Reflections on ‘Risk’, Hazards’ and Life Choices*, in *RISK AND SOCIOLOGICAL THEORY*, *supra* note 236, at 1, 4-6 (arraying sociocultural risk scholarship ranges from realist to relativist).

²⁴² BECK, *supra* note 122, at 31.

²⁴³ See Eric Dash, *If It’s Too Big To Fail, Is It Too Big To Exist?*, N.Y. TIMES (June 21, 2009), <http://www.nytimes.com/2009/06/21/weekinreview/21dash.html> (explaining popularization of phrase).

²⁴⁴ See Brief of Petitioner at 4, *Mut. Pharm. Co. v. Bartlett*, 133 S. Ct. 2466 (2013), 2013 WL 457382, at *4 (describing the balance Congress sought to strike between cost and safety in the Hatch-Waxman Act); see also Jan Crawford, *Can a Patient Sue a Generic Drug*

However, conceptions of risk can evolve so that something that was previously seen as individual cost or misfortune comes to be thought of as a salient social risk. John Witt describes this type of transformation behind the creation of workman's compensation.²⁴⁶ Workplace injuries occurred before industrialization, but by the end of the nineteenth century they manifested in more frequent, more devastating, and more visible ways.²⁴⁷ In light of this evolution, advocates worked to transform workplace injury from something conceived of as a source of individual misfortune or fault to a risk inherent in industrialization. This was achieved by framing the injuries as an unavoidable threat to the economic security of American families.²⁴⁸ This framing made a collective solution seem imperative. In turn, the creation of a collective approach to pay for workplace injuries became the springboard for a "new conception of social responsibility . . . that aimed not just to spread the risks of injury, but also to take on more fundamental risks such as poverty."²⁴⁹

The idea of social responsibility to address such risks laid the foundation for the New Deal, creating what one scholar characterized as a "palpable experience of solidarity that helped underwrite the forms of collectivism that were successfully implemented."²⁵⁰ In fact, risk displaced other justifications for state support, as part of what has been described as a modern shift from a "welfare society" to a "risk society."²⁵¹ Costs understood to be the result of uncontrollable threats to family or individual security made a greater claim to state resources.²⁵² Redistribution was not the explicitly stated goal; security was.

As other harms were perceived as similar in nature to workplace injury—unavoidable and significant—they became worthy targets for social insurance.²⁵³ For example, as hospitals modernized and medical care became

Manufacturer?, CBS NEWS (Mar. 19, 2003), http://www.cbsnews.com/8301-18563_162-57575231/can-a-patient-sue-a-generic-drug-manufacturer.

245 See Martha McCluskey, *supra* note 23, at 146 (describing a shift from concern with the risk faced by workers to that by employers and big business, affected partially by fixation on moral hazard).

246 WITT, *supra* note 24.

247 *Id.* at 24.

248 *Id.* at 129-30 (describing how activist Crystal Eastman transformed the debate of workplace accidents from centering on individual fault to "the image of the wounded family").

249 *Id.* at 150.

250 Simon, *supra* note 23.

251 BECK, *supra* note 124, at 19-20.

252 See Landis, *supra* note 24, at 271; LANDIS DAUBER, *supra* note 24; Ewald, *supra* note 239, at 209-10; Ewald, *supra* note 24, at 281 ("It is a commonplace that, during the twentieth century, law and responsibility were transformed, bit by bit, into a legal system of compensation, based on risk and insurance.").

253 WITT, *supra* note 24, at 5 ("[T]he industrial-accident crisis introduced to the American legal system new ideas and institutions organized around risk, security, and the actuarial

both more expensive and more effective, the costs of medical care threatened American families' financial security, and insurance for medical care was needed to protect the family wage. Medicare and Medicaid were enacted. The creation of Social Security was in part based on the recognition that longer lives heightened the risk of a family outliving its savings and understanding this problem as a collective scourge and not as individual misfortune. Each of these challenges that had long been managed mostly privately came to be perceived as proper zones of state support.

In turn, the creation of social insurance to manage a particular harm helped to transform the social understanding of these harms from a private obligation to a collective concern. Ewald describes that insurance "makes risks appear where each person had hitherto felt obligated to submit resignedly to the blows of fortune."²⁵⁴ He calls this transformation the process of the "insurantal imaginary,"²⁵⁵ implying that the creation of insurance itself affirms a particular harm as risk.

In recent years, the language of risk has often been coopted by those who take the position that it is an individual's responsibility to manage risk. Risk spreading approaches are crumbling under the weight of moral hazard—the idea that too much insurance discourages efficient caution.²⁵⁶ Jacob Hacker, in *The Great Risk Shift*, calls this trend the "personal responsibility crusade" and shows how it has led to policies that invisibly undercut Americans' economic security.²⁵⁷ As risk has become so strongly associated with this neoliberal agenda, some scholars seek a new language to advocate for state policies that can increase security.²⁵⁸

But proponents of social change should not reject the language of risk; it has a long history of motivating monumental social policies and in the right

categories of insurance—ideas and institutions that to this day remain at the heart of much of our law"); Landis, *supra* note 24, at 271 (1999) ("Ultimately, whether or not an event was a 'calamity' deserving of federal intervention turned upon the ability of the claimants to argue that they, like those who previously received aid, were innocent victims of fate rather than irresponsible protagonists in their own misery."). See generally LANDIS DAUBER, *supra* note 24 (describing government indemnification of victims of natural disasters that were considered calamitous and unpredictable).

²⁵⁴ Ewald, *supra* note 239, at 200.

²⁵⁵ *Id.* at 209-10 (describing risk as "the principle of a new political and social economy" beginning at the end of the nineteenth century with the rise of social insurance).

²⁵⁶ See e.g., BAKER & SIMON, *supra* note 23; HACKER, *supra* note 23.

²⁵⁷ HACKER, *supra* note 23, at 8. Jonathan Simon attributes this shift to the public obsession with new threats that defy risk-spreading solutions, such as climate change, crime, and cancer. Risk spreading solutions "no longer undercut the dread associated with [these threats]" and the harms that resulted are not perceived as a necessary price to pay for something "profoundly good for society." Simon, *supra* note 23, at 128, 135.

²⁵⁸ Martha Fineman, "Elderly" as Vulnerable: Rethinking the Nature of Individual and Social Responsibility, 2 ELDER L.J. 101, 136-38 (2012) (advocating for focus on "vulnerability" instead of "risk").

context could do so again. As Hacker suggests: “Americans may be willing to turn a blind eye to growing inequality, confident in the belief that their own standard of living is still rising. But economic insecurity strikes at the very heart of the American Dream.”²⁵⁹ It leaves even those who have done all the right things to achieve a place in the middle class fearful about having the rug pulled out from under them.

The idea of next-friend risk recasts the problem of private obligation for long-term care in a more compelling way for the public and for policymakers, many of whom worry personally about the possibility of becoming responsible for an aging parent, sick spouse, or disabled child. Recognizing next-friend risk can transform long-term care from an old-people problem into a universal concern. Public long-term care funding has been vulnerable to attack as “yet another” transfer from today’s already stretched workers to the elderly. If instead we see the problem of long-term care as a threat to people’s financial security and health during their prime earning and child-rearing years, solving it, in effect, is a transfer to the young, working class. Three-quarters of informal caregivers are under age sixty five and three-fifths are in the labor force.²⁶⁰ In other words, any social resources and tax dollars spent on the problem would benefit the primarily working-age next friends as much as the care recipients. Seeing long-term care as a problem equally for care recipients and for next friends could broaden coalitions for reform, uniting the interests of labor, informal caregivers, older voters, and disability advocates.

Next-friend risk, however, has been sidelined. The policy focus on long-term care risk from the care-recipient perspective has served to overshadow the concomitant risk to next friends. The laws and policies described in Part I have hidden next-friend risk from the public eye, in the home and off the balance sheets, by inscribing it as private and individual—unsurprising, given the gendered nature of long-term caregiving. The notion that family care is a personal, perhaps moral, obligation that people provide willingly is politically convenient. It has enabled policymakers to avoid dealing with the full cost of long-term care, instead leaving others to experience the costs privately and invisibly.

E. The Implications of Imagining Next-Friend Risk

Understanding the possibility of becoming responsible for another as a social risk—and not as a private obligation—has at least four major substantive implications for long-term care policy.

²⁵⁹ HACKER, *supra* note 23, at 15.

²⁶⁰ Chari et al., *supra* note 26, at 876.

First, it changes the scale of the problem. Current social insurance policy hides costs borne by next friends. Even considering just the \$470 billion estimate of the current market value of hours spent caregiving would require long-term care funding at triple current Medicaid levels.²⁶¹ Although the United States spends more per capita than other developed countries on nearly every other category of health care, it spends comparatively less on long-term care.²⁶² There is good reason to spend more. Even if Medicaid funding is unlikely to triple anytime soon, accurate accounting of the size of the problem could anchor policymakers on a more realistic number.

Second, as discussed just above, recognizing the problem of next-friend risk highlights its similarity to other problems that have prompted the creation of social welfare policy and social insurance to spread risk. At a moment in time when individualistic sentiment runs strong, the fact that many people can relate personally to next-friend risk could be a boon.²⁶³ In other words, people might be motivated out of self-regard to support a solution that offers communitarian benefit. More so, where intensive care needs persist over time, few Americans could shoulder the burden privately, suggesting the necessity of a universal social insurance approach. Universal programs are also more popular and less politically vulnerable than means-tested ones, like Medicaid.

Third, even with an infusion of funding, it is necessary to see the problem from the perspective of next friends in order to design policy with the flexibility to mitigate the risk they face. Next-friend risk could be mitigated to some extent by simply increasing Medicaid funding for long-term care, but even a large increase could have limited benefit if not done with an eye toward addressing next-friend risk.

In some cases, the best way to mitigate risk is to make family caregivers whole by paying them for caregiving. In others, it is by enabling them not to

261 Reinhard et al., *supra* note 26, at 2.

262 MCKINSEY CTR. FOR U.S. HEALTH SYS. REFORM, ACCOUNTING FOR THE COST OF U.S. HEALTH CARE: PRE-REFORM TRENDS AND THE IMPACT OF THE RECESSION 9 (2011), http://healthcare.mckinsey.com/sites/default/files/793268_Accounting_for_the_Cost_of_US_Health_Care_Prereform_Trends_and_the_Impact_of_the_Recession.pdf (estimating that the United States spends almost \$275 billion less than expected on long-term and home care, meaning that just spending at expected would double the current U.S. spending levels; for comparison, the United States spend \$522 billion more than expected (approximately 50% more) on outpatient care and \$120 billion more than expected (approximately 30% more) on drugs and nondurables); *see also* David Squires & Chloe Anderson, *U.S. Health Care from a Global Perspective: Spending, Use of Services, Prices, and Health in 13 Countries*, COMMONWEALTH FUND 7-8 (2015), <http://www.commonwealthfund.org/publications/issue-briefs/2015/oct/us-health-care-from-a-global-perspective> (showing that the United States spends relatively more on health care and less on social services than comparable studies).

263 *Cf.* Walter Korpi & Joakim Palme, *The Paradox of Redistribution and Strategies of Equality: Welfare State Institutions, Inequality, and Poverty in the Western Countries*, 63 AM. SOC. REV. 661, 664-65 (1998) (suggesting that redistributive institutions have societal feedback effects).

provide care in the first place and thus limit the extent of the negative impact on their careers or lives. It is possible to mitigate risk fully from the care-recipient perspective, but to leave next friends vulnerable by, for example, pouring money into current Medicaid programs that have a bias for family care. Even if Medicaid compensated all hours of informal care at a fair wage, it would perpetuate harm—financial and nonmonetary—for kin who are better off in the long run if they do not provide care, but who have no other option. Conversely, if a huge infusion of funding were made available only to pay for outsourced care, the same would occur. Some people would be unable to find a satisfactory way to pay for care and would instead provide care themselves, even without pay. Or under some states' policies, the only outsourcing option is nursing home care. Someone unwilling to put a parent in a nursing home, or whose parent is unwilling to live in a nursing home, might instead still provide care herself.

When someone becomes responsible for the care of another, she should be able to decide whether to provide care herself or to pay someone else to do it (or some combination). Insurance must be designed to enable a next friend to toggle more freely between these two choices and thus to use benefits in a way that minimizes her own insecurity, however she might define it, and to balance caring for a family member with other pursuits. Current policy is focused so narrowly on care-recipient risk that it does not even see the need for this toggle. I discuss in detail below why such a toggle is imperative and what it requires. Conceptually, seeing next-friend risk reveals the need for it.

Fourth, especially if no additional money is spent, understanding next-friend risk raises the (admittedly uncomfortable) question of whether we should think differently about tradeoffs between mitigating care-recipient and next-friend risk, even if it means compromise in some cases for the care recipient. For example, if an elderly widower has a stroke, the goal of current long-term care law and policy is to protect his autonomy by providing adequate support in the least restrictive setting appropriate, as required by *Olmstead*.²⁶⁴ If his daughter moves him into her home—the solution that Medicaid policies for home- and community-based care increasingly encourage—this goal could be fully met at the lowest possible *public* cost. But his daughter may have to reduce working hours or leave a secure job with benefits, threatening her family's long-term finances and possibly health and wellbeing. Such results, where each generation sacrifices its security for the previous one, are simply not sustainable.

264 *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 607 (1999).

As the demands for care are becoming more intense and the structure of families is changing, care needs do not fit seamlessly into the household, and the risk long-term care poses to next friends is increasingly difficult to ignore. When viewed in the aggregate, next-friend risk appears as threatening as the risk of disability from the care recipient perspective and as many of the other phenomena that have motivated state action.

No social policy could neutralize all of the harm people experience when friends or family need long-term care. It is inevitably painful to see a loved one who needs help feeding herself or getting in and out of bed, even if the costs of her care are fully compensated. Nor could any policy even ameliorate all economic harms. Doing so would be too complex and too expensive. But long-term care policy could be designed to minimize next-friend risk better than it does today. Considering the risk of long-term care equally from this perspective is a first step toward better long-term care policy.

III. SOCIAL INSURANCE FOR NEXT-FRIEND RISK

A. *The Case for Social Insurance for Next-Friend Risk*

Imagining next-friend risk implies that it is something social insurance *could* mitigate. Here, I make the case for why it *should*. Social insurance spreads costs that a society sees as inefficient, undesirable, or unjust for an individual to bear. It can be used to promote economic efficiency or address private-insurance market failures.²⁶⁵ Social insurance can also “change [the] character” of an existing market,²⁶⁶ such as when people cannot afford private insurance that would be welfare enhancing,²⁶⁷ for paternalistic reasons, or to advance social justice goals.²⁶⁸ Social insurance policies that are more sensitive to next-friend risk could be more efficient and result in a more just distribution of the costs of long-term caregiving. As will be discussed in Part IV, these goals could be advanced by a comprehensive social insurance program or even just incremental changes to existing social insurance policies.

²⁶⁵ See KENNETH ABRAHAM, *DISTRIBUTING RISK* 10 (1986); GRAETZ & MASHAW, *supra* note 24, at 18; MOSS, *supra* note 24, at 10-13 (suggesting reasons why risk-related market failures are common); Kwak, *supra* note 27, at 12.

²⁶⁶ See GRAETZ & MASHAW, *supra* note 24, at 18;

²⁶⁷ See Steven Shavell, *A General Rationale for a Governmental Role in the Relief of Large Risks*, J. RISK & UNCERTAINTY (forthcoming), https://dash.harvard.edu/bitstream/handle/1/16883007/Shavell_768.pdf.

²⁶⁸ GRAETZ & MASHAW, *supra* note 24, at 18-23; *see also* ABRAHAM, *supra* note 265, at 20-29 (1986) (distinguishing egalitarian justifications from utilitarian ones because they have equality at their center and not as a potential byproduct). Abraham describes libertarianism as a third influence, in addition to utilitarianism and egalitarianism, and contends that “intuitive pragmatism,” a mix of these three values, informs insurance regulation. *Id.* at 29.

Mitigating next-friend risk would serve a core utilitarian goal—to protect people from income loss that can undermine economic security.²⁶⁹ Marmor and coauthors describe social insurance as “a set of interventions designed to reduce the impacts of common threats across each person’s life cycle, threats that simply cannot be countered effectively by individual prudence and private markets.”²⁷⁰ As explained above, next-friend risk poses precisely this type of threat.

Yet, social policy does not always intervene to make lives more secure, even if it could, which raises the question of why next-friend risk should be a priority. Family or friends often take responsibility for each other in cases of, for example, unemployment, property damage, or unmanageable debt. Furthermore, U.S. social welfare policy excludes most caregiving, even though spreading the costs of such activity has the potential for significant welfare benefits.²⁷¹

One possibility is that next-friend risk in the case of long-term care is not exceptional, and the state should be equally concerned with costs family face in these other situations. Policymakers select out some from among many insurable risks.²⁷² From this perspective, what becomes insured is more a matter of what suits a social and political moment than any valid comparative claim to shared resources.

Yet, there are also substantive reasons why addressing next-friend risk is especially important. As Section II.A described, the social norms for taking care of a family member or friend who is physically vulnerable are strong and engender sacrifice. It is less expected that a family member would sacrifice her own financial security, family, career, or wellbeing to bail a sibling out of credit card debt or to bankroll an unemployed child indefinitely. Next-friend risk arises in service of something that we expect people to do and that we perceive as a public benefit: providing care for people with serious illness or disability.²⁷³

Furthermore, the consequences of not helping a sibling in credit card debt are less dire, in part because the law and private insurance already offer means for relief. A family member in debt can file for bankruptcy. Someone who loses a job can claim unemployment insurance. But in the case of long-

269 *E.g.*, GRAETZ & MASHAW, *supra* note 24, at 45.

270 MARMOR ET AL., *supra* note 24, at xx.

271 Alstott, *supra* note 141, at 27; *See generally* HACKER, *supra* note 23 (making the case for stronger social insurance programs to spread risk).

272 GRAETZ & MASHAW, *supra* note 24, at 25 (“Social insurance . . . is defined concretely for any society by the complex interaction of collective purposes and acceptable political techniques.”). Ewald calls this process the combination of insurantal imaginary and political imaginary. Ewald, *supra* note 239, at 198.

273 Simon, *supra* note 23, at 128, 135.

term care, it is nearly impossible for people to meet their needs without others' help, even if they qualify for Medicaid benefits.

Next-friend risk has higher stakes. Just the possible monetary losses outlined above can set a caregiver up for a future with insufficient resources to meet her own basic needs. Few ways that family members aid each other approach this level of cost and financial insecurity. Addressing next-friend risk could thus significantly bolster the financial security of American families.

Social insurance also serves egalitarian goals. John Rawls argued that a just distribution of basic resources is defined by the share held by the worst off person in society.²⁷⁴ Social insurance offers protection against the depletion of any one individual's basic resources. Graetz and Mashaw justify social insurance in such terms: "Given little information about where they would start or end up in the income distribution, it might seem in everyone's interest to agree to the collective provision of affordable . . . insurance in order that they all have reasonable protection against foreseeable risks."²⁷⁵ Anne Alstott has expressed a similar goal in "liberal egalitarian" terms. She contends that "a central function of the state is to create institutions that ensure to every person the conditions of autonomy: the chance to develop the capabilities that one needs to formulate, choose, and pursue a vision of the good life."²⁷⁶ Social insurance can serve as such an institution that protects conditions of autonomy, in terms of money or time.

Although people disagree on what particular basic resources or conditions are necessary to ensure opportunity,²⁷⁷ it is indisputable, under any definition, that responsibility for another's long-term care would deplete these resources and disrupt such conditions. Just the potential financial losses would do so. Yet, long-term caregiving also depletes health and time, which are as

²⁷⁴ See JOHN RAWLS, A THEORY OF JUSTICE 72 (1971); RONALD DWORKIN, SOVEREIGN VIRTUE 73 (2000).

²⁷⁵ GRAETZ & MASHAW, *supra* note 24, at 19.

²⁷⁶ ALSTOTT, NO EXIT, *supra* note 22, at 35.

²⁷⁷ Professors Graetz and Mashaw focus on economic resources. See GRAETZ & MASHAW, *supra* note 24, at 19. John Rawls himself names liberty as the foremost primary good. See RAWLS, *supra* note 274, at 214. Norm Daniels extends Rawls's analysis to health as a condition of equality. NORMAN DANIELS, JUST HEALTH (2007). Amartya Sen and Martha Nussbaum contend that capabilities are better precursors to opportunity because they capture how people with various levels of ability actually engage in the world. Martha C. Nussbaum, *Long-Term Care and Social Justice: A Challenge to Conventional Ideas of the Social Contract*, in WORLD HEALTH ORG., ETHICAL CHOICES IN LONG-TERM CARE: WHAT DOES JUSTICE REQUIRE? 31 (2002); Amartya Sen, Equality of What?, The Tanner Lecture on Human Values (May 22, 1979), http://tannerlectures.utah.edu/_documents/a-to-z/s/sen80.pdf. Nussbaum includes goods such as "entitlement to leisure for play and the cultivation of one's faculties, political participation, and employment opportunities" among the basic "primary goods." Nussbaum, *supra*, at 56.

necessary as money as conditions to pursue life goals. Research shows that even those caregivers who see caregiving as part of their purpose in life and report personal enrichment from it are no less likely to suffer a loss of identity, referred to tellingly as “loss of self” or “role engulfment.”²⁷⁸

These harms are made especially unjust by the fact that they are borne inequitably, especially by women. Their long-term care responsibilities exacerbate weaker workplace attachment and the wage gap. Social policy sensitive to next-friend risk could promote conditions of autonomy for everyone and, in so doing, also reduce the disparate impact of next-friend risk on women’s careers, earnings, health, and wellbeing.

B. Principles To Guide the Design of Social Insurance for Next-Friend Risk

Designing social insurance in a way that promotes greater security and simultaneously protects a next friend’s ability to make life choices is not simple. Imagine if the state were to provide all long-term care in-kind, perhaps with the option for either nursing home care or formal caregivers at home. This approach could reduce the insecurity that informal caregivers face, by taking them out of the business of long-term caregiving altogether. They would be free to engage in their professions, child-rearing, civic work, education, and leisure activities, as before, and to spend time with a friend or family member as they wish but not as the primary caregiver. This approach is conceptually simple. Yet, it would be both difficult to implement, at least in the short term, and incomplete. Even with the current reliance on family and friends, there is a substantial shortage of formal care providers, as discussed below. No feasible path forward could cut all family and friends out, especially in the short term.

Further, providing only in-kind benefits would not achieve the goal of greater security for everyone.²⁷⁹ Some people would decline an in-kind benefit to provide unpaid informal care themselves, either because they want to do so or because a family member refuses anything but family care. Even if someone deeply values providing care—enough to do it for free when other options exist—we might nonetheless want to protect her from experiencing insecurity if she chooses to do so, especially if we value caregiving by friends and family. In other words, we might not want Mother Teresa to die homeless and starving just because she truly preferred to care for others for free.

278 Marilyn M. Skaff & Leonard I. Pearlin, *Caregiving: Role Engulfment and the Loss of Self*, 32 GERONTOLOGIST 656, 657 (1992). “Loss of self” was found to be more common among spouses, women, and younger caregivers. *Id.* at 660.

279 It might, however, be a more effective way to achieve other goals, such as stronger workplace attachment for women and narrowing the gender gap in the workplace.

Likewise, for all of the reasons already articulated, shifting to a system of only family care, even if compensated, would not be a good solution either. It would require more people to disrupt other pursuits, even when doing so is not in their best interests.

A comprehensive approach must recognize and support the two ways that someone could respond to a family member or friend in need—by providing or paying for care. The best policies would be designed to allow someone to toggle between these two choices, to protect her security and, equally, her self-determination.

One version of a toggle might require social insurance policies that are neutral on their face. Policies could allow next friends to use benefits interchangeably to provide care or to pay someone else to do so. This approach is common in other countries with universal long-term care insurance.²⁸⁰

Each next friend could weigh potential harms and benefits and decide how best to minimize her own risk in a context where harms and perceptions of harms vary considerably from person to person. For example, imagine a daughter is working toward a master's degree in business or is writing a novel when her father has a stroke. She might, on one hand, believe that finishing her degree or the novel is the best way to protect her future security or to pursue her dreams. Or she might prefer to put these pursuits on hold. More facially neutral long-term care policies would at least give her the opportunity for such deliberation.

Furthermore, more flexible policies are sensitive to the complexity of factors that go into such decisions, balancing the needs of care recipients and their next friends. In some cases, the care recipient might prefer care by a friend or family, or family might be better able to address a care-recipient's needs.²⁸¹ Some studies suggest that treatment outcomes can be better when a loved one provides care.²⁸² In other cases, it might not be best for a family member to provide care, such as when more specialized care is needed, when a parent was or is abusive, or when the parent is reticent to burden family or friends with caregiving but willing to accept paid, professional help. In many cases, a combination of providing and paying for care might be best. As Carol Levine, a prominent long-term care scholar and the primary caregiver for seventeen years for her husband, who was paralyzed from the neck down in a

²⁸⁰ See discussion *infra* Section IV.A.2 for examples of this approach.

²⁸¹ See, e.g., Wolf, *supra* note 146, at 366-67 (contending that a family member might be better positioned to manage money or prepare meals or to generate economies of scale with cohabitation).

²⁸² See, e.g., Joseph E. Gaugler, *Family Involvement in Residential Long-Term Care: A Synthesis and Critical Review*, 9 *AGING & MENTAL HEALTH* 105, 111 (2005) (reporting that family involvement in caregiving has been shown to decrease mortality, infection, and hospitalization).

car accident, aptly describes: “Total self-sacrifice may be ennobled in legend; it is a decidedly unsatisfactory way to live one’s life and a poor basis for public policy.”²⁸³ The point is that there is no single right answer on how to structure long-term care provision for every circumstance. Policies must be designed in a way that creates space for this variability.

Simply creating an option to outsource care in more cases would change the landscape by softening the way that the law currently creates a bias toward informal caregiving. As Gillian Lester has explained: “[I]f a state intervention makes a choice previously unavailable to some portion of the population financially more attractive, the effect will be to encourage individuals on the margin toward the new option.”²⁸⁴ We might think of a toggle that creates facially neutral policies as a “thin version” of state neutrality. The goal would be to strive for policies that do not, in and of themselves, strongly bias decisions on how to manage next-friend risk.

Yet a policy that is neutral on its face would not mean neutral grounds for decisionmaking when layered on top of strong preexisting biases toward familial care—individual, social, or institutional. A “thick version” of state neutrality could provide some counterweight to these biases.

For example, individuals might underestimate the burdens of long-term caregiving and overestimate the benefits.²⁸⁵ People might underestimate the long-term effect on career advancement or the many sources of income and assets that will be compromised, including health benefits, social security, or pensions. They could easily underestimate the length of time care will be needed; elderly parents suffer diseases that can persist for many years, yet doctors cannot provide good estimates of likely mortality.²⁸⁶ Likewise, next friends might suffer from “optimism bias” and overestimate the benefits of providing care personally, including psychic rewards, possible inheritance, or even the benefit to the care recipient of family providing care.²⁸⁷ Or the horror stories about problems that arise in nursing homes might be overly influential.²⁸⁸

²⁸³ Levine, *Home Sweet Hospital*, *supra* note 124, at 348.

²⁸⁴ Lester, *supra* note 125, at 6.

²⁸⁵ Cf. Christine Jolls et al., *A Behavioral Approach to Law and Economics*, 50 STAN. L. REV. 1471, 1476-79 (1998) (describing the research on bounded rationality—the reasons why actual behavior differs from rational behavior); Russell Korobkin & Thomas Ulen, *Law and Behavioral Science: Removing the Rationality Assumption from Law and Economics*, 88 CALIF. L. REV. 1051 (2000) (outlining empirical evidence inconsistent with the rationality assumption).

²⁸⁶ Cf. Korobkin & Ulen, *supra* note 285, at 1083 (describing the possibility for suboptimal decisionmaking in ambiguous situations).

²⁸⁷ Neil D. Weinstein, *Unrealistic Optimism About Future Life Events*, 39 J. PERSONALITY & SOC. PSYCHOL. 806, 806 (1980).

²⁸⁸ Cf. Korobkin & Ulen, *supra* note 285, at 1100 (describing “anchoring” errors); Jennifer Steinhauer, *Shock but No Longer Surprise over Nursing Home Problems*, N.Y. TIMES

Furthermore, the background social norms and social institutions discussed in Part II create a non-neutral and self-reinforcing baseline that could overly determine decisions, especially decisions women make to provide care directly. The historical reliance on family caregiving has limited investment in compelling community-care settings and has atrophied the labor force for caregiving, which means that even with nimble policies, it may still seem there is no option but to provide care.

Policies could be designed to be sensitive to and with the aim of counterbalancing these preexisting biases.²⁸⁹ At the very least, they could make transparent the costs and benefits of different choices to prompt people to consider them.²⁹⁰ Medicaid policies could highlight the benefit of care in group settings or from formal caregivers, who are often better trained or equipped to provide care, and the burdens family face when providing care personally. Even more strongly, the law might, for example, be designed to discourage untrained next friends from providing care in the hardest cases, such as with dementia care, where caregivers report the highest burden.²⁹¹ Thus, there are compelling reasons to increase social insurance protections for next friends, but actually doing so is no easy task.

C. Policymaking and Dynamic Effects

Just as current policies compel informal caregiving, new policies would shape decisions as well, whether intentionally or not. Policymakers try to predict individual and social responses to policies—dynamic effects—but are not always able to do so perfectly. And these effects might change in response to changing social circumstances, requiring iteration over time to achieve policy goals.

In the case of policies aimed to address next-friend risk, social policy details could have dramatic effects on workplace participation, the future development of long-term care facilities and workforce, and kinship

(Nov. 9, 2000), <http://www.nytimes.com/2000/11/09/nyregion/shock-but-no-longer-surprise-over-nursing-home-problems.html> (noting a 30% increase in citations for inadequate care in nursing homes between 1998 to 1999).

289 See Christine Jolls & Cass R. Sunstein, *Debiasing Through Law*, 35 J. LEGAL STUD. 199, 199-201 (2006) (describing use of the law to steer people toward more rational decisions).

290 This type of informational approach is common in financial literacy efforts. See Allison K. Hoffman & Howell E. Jackson, *Retiree Out-of-Pocket Healthcare Spending: A Study of Consumer Expectations and Policy Implications*, 39 AM. J.L. & MED. 62, 65-66 (2013) (describing these financial literacy efforts).

291 JOSHUA M. WIENER ET AL., AARP PUB. POL'Y INST., CONSUMER-DIRECTED HOME CARE IN THE NETHERLANDS, ENGLAND, AND GERMANY 15 (2003), http://assets.aarp.org/rgcenter/health/2003_12_eu_cd.pdf. In these cases, relying on professional caregivers might be in the best interests of both the care recipient and the next friend.

relationships. This Section acknowledges such effects by considering one especially important policy design question: whether to compensate care a next friend provides based on lost income or market caregiving wages. This decision in effect gets to the heart of how exactly we conceive of the insurable harm—disruption of employment or time spent caregiving—and would have a significant impact on an individual's decision to provide or pay for care. This discussion is not intended to solve this question, which has fueled decades of feminist debate; rather, I use it to illustrate the importance of policy details.

The first approach, replacing lost income, captures immediate financial harm in a way familiar to American social insurance, which most often measures harm as the costs of disruption of paid work.²⁹² This approach, however, implies that an at-home parent, a volunteer worker, or an unemployed worker, who would not experience immediate loss of income, is not harmed.²⁹³ It also takes a snapshot view of harm that does not capture the cascading effects caregiving might have on someone's life. If a mother were caring for her young children but intending to return to work, added responsibility to care for an aging parent or injured spouse could be the final straw that prevents her from ever reengaging in paid work.²⁹⁴ Basing benefits on potential future lost wages would be pure speculation, even if such losses might have been significant. On the other hand, if a corporate executive took leave to provide care, social policy would put a high value on the harm, and the public costs of doing so would be formidable. The fact that the market values some activities more than others would be felt doubly. Social insurance policy that views harm only in terms of lost wages would replicate the wage gap and undervaluation of women's work.²⁹⁵

This approach would have cascading effects. Lower-paid or unemployed family members, more likely women, would have less incentive to take on caregiving, and they would be paid less when they do. And all else equal, a

292 See GRAETZ & MASHAW, *supra* note 24, at 27. But see Allison K. Hoffman, *Three Models of Health Insurance: The Conceptual Pluralism of the PPACA*, 159 U. PA. L. REV. 1873, 1890-91 (2011) (describing that social insurance can be focused on harms other than disruption of paid work, including on harms to health).

293 Cf. Alstott, *supra* note 141, at 6 (“[O]nce we understand social insurance as the use of law to address, in a deliberate way, the major risks of life, then the focus of present programs on the risks of paid employment begins to seem oddly narrow.”).

294 See, e.g., Skira, *supra* note 18 (describing the longitudinal effect of informal caregiving for aging parents on women's labor participation). Most women who stay home with children later return to work. JENNIFER CHEESEMAN DAY & BARBARA DOWNS, U.S. CENSUS BUREAU, *OPTING-OUT: AN EXPLORATION OF LABOR FORCE PARTICIPATION OF NEW MOTHERS* 4 (2009) (reporting that although half of women with children under 12 months are not employed, most are employed by the time the child is over 12 months).

295 See *supra* note 125.

higher earner could more freely make a decision to provide care with less financial sacrifice.

This approach would also face practical challenges. Benefits with a higher dollar value could increase concerns of moral hazard or fraud. Plus, it would be difficult to administer and finance benefits based on individual lost wages, especially if a substantial number of higher-earners took on caregiving roles. Realistically, full wage replacement is infeasible, but partial replacement is conceivable. As an example, California is one of three states with a disability program designed to compensate family caregiving by replacing lost income—the others are Rhode Island and New Jersey. In 2016 in California, which has the most generous of the three programs, the program reimburses caregivers fifty-five percent of lost earnings, but up to a maximum of \$1129 per week and only for six weeks total.²⁹⁶ Of course, anything less than full wage replacement relatively reduces incentives to take leave from work to provide care.

The other approach would be to compensate the hours a next friend spends caring for another at market caregiving wages. Symbolically, this approach values hours spent in terms of the service provided instead of in terms of opportunity costs.

This approach would also have strong dynamic effects. It creates greater incentives for people with lower or no salary to provide care and for higher earners not to do so. Benefits would be a job engine for the unemployed or underemployed. At the same time, this approach would perpetuate the existing gendered division of care work. Even more, it could actively discourage women from pursuing work outside of the home, by making home-based work relatively more attractive than it is now. It would reinforce expectations that the lower-earning family members (more often women) take on caregiving and that the higher earners stay in their more lucrative position. Yet, if benefits are fungible and could be used just as easily to outsource care, the lower-earning member still gains leverage, as compared to the status quo, to resist expectations that she be the one to provide the care.

On balance, paying for hours based on market wages, or, even better, a living wage²⁹⁷ might be preferable. The value of benefits for home-based care would be the same regardless of whether someone chooses to provide or pay for the care. Someone would have to value providing care more than her status

²⁹⁶ *About Paid Family Leave*, ST. CAL. EMP'T DEV. DEP'T (2016), http://www.edd.ca.gov/disability/About_PFL.htm.

²⁹⁷ The median hourly wage for direct care workers was \$10.63 in 2012. *America's Direct-Care Workforce: November 2013 Update*, PARAPROFESSIONAL HEALTHCARE INST., 2 (2013) [hereinafter *America's Direct-Care Workforce*], <http://phinational.org/sites/phinational.org/files/phi-facts-3.pdf>. A full-time job at this wage is just over \$21,000. For criticism of the structure of paid caregiving work, see sources cited *supra* note 126.

quo position (including any wage differential) to take it on personally, or else she could pay someone else to do it. Higher earners would still have incentive to outsource, rather than provide care, but the two options would be more comparable than in today's world with no compensation for informal caregiving in most cases. Even if this approach replicates incentives for people without wage jobs or with lower-paid jobs to take on caregiving, they would, at the least, receive monetary compensation for work they already do now without pay. To avoid this replication would require either a thick version of state neutrality that discourages people from informal caregiving altogether or policies that address the sources of underlying bias in more substantial ways.

This example illustrates how the notion of creating neutral policies may be simple in concept but not in application. The best policymakers can do is to design the most evenhanded policy possible and monitor and reconsider the effects of policy decisions over time.

D. Considerations for What Counts as Next-Friend Risk

Even those who, in theory, favor social insurance for next-friend risk might disagree on what exactly should qualify as insurable risk. Some activities seem routine and others less so. How do we know when an adult child caring for a parent is at risk as compared to just doing what children do for their parents? Is it risky simply to be responsible for another's care or only when someone lacks the resources to manage such responsibility?

These types of boundary questions undergird all insurance design, private and social. The answers determine which costs will be shared and which should remain private obligations.²⁹⁸ For example, the ACA requires insurers to charge most insured individuals similar premiums, but allows them to charge smokers higher premiums.²⁹⁹ Expressively, this policy signals a belief that smokers have increased their chances of harm and thus should remain privately responsible for more costs.³⁰⁰ Often the principle of choice is

298 Tom Baker, *Risk, Insurance, and Responsibility*, in EMBRACING RISK, *supra* note 23, at 33, 45-46 ("Depending on the degree to which premiums or benefits are linked to individual characteristics or choices, the fortunes of the members of an insurance group can be linked together to a greater or lesser extent.").

299 Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111-148, § 2701(a)(1)(A)(iv), 124 Stat. 119, 155 (codified as amended at 42 U.S.C. § 300gg(a)(1)(A)(iv) (2012)).

300 An economist would describe this behavior as moral hazard and its exclusion as efficient. *But see* Tom Baker, *Insuring Morality*, 29 ECON. & SOC. 559 (2000) (arguing that this neoclassical economic version of insurance has embedded in it notions of morality).

invoked to justify what is in or out: those costs that result from personal choices should be private, while stochastic harms should not.³⁰¹

Line-drawing decisions are inevitably normative and often highly contested.³⁰² These determinations are high stakes, in part because they serve to shape how we think about social problems.³⁰³ Richard Ericson writes: “In making risks collective and commodified, insurance alters notions of providence, responsibility and justice.”³⁰⁴ For example, Medicare freed employers from responsibility for retiree health care spending.³⁰⁵ Conversely, the lack of cohesive state systems for long-term care insurance tacitly affirms private responsibility. The boundaries of any new approach to insure next-friend risk will likewise shape how people think about responsibility for long-term care for years to come.

In this Section, I do not attempt to firmly draw these boundaries, although I suggest that some lines are easier to defend than others. My main aim is to identify the places where the difficult questions arise and what is at stake when lines are drawn.

1. *Who Bears Next-Friend Risk?*

The paradigmatic case of long-term care is that of an adult child caring for an aging parent, but only about half of cases fit this picture.³⁰⁶ Consider the following scenarios:

A young girl is diagnosed with autism. She will require significant care for her entire life. She has two siblings, and both parents work to earn enough to support the family. (Lifelong-Care Scenario)

301 See Seana Valentine Shffrin, *Egalitarianism, Choice-Sensitivity, and Accommodation*, in REASON AND VALUE: THEMES FROM THE MORAL PHILOSOPHY OF JOSEPH RAZ 270 (R. Jay Wallace et al. eds., 2004).

302 Noah D. Zatz, *Poverty Unmodified?: Critical Reflection on the Deserving/Undeserving Distinction*, 59 UCLA L. REV. 550 (2012) (discussing the normative judgment involved in defining “need”).

303 RICHARD V. ERICSON ET AL., INSURANCE AS GOVERNANCE 50 (2003) (studying private insurance as a form of “governance” outside of the bounds of the state).

304 *Id.* at 48.

305 See STARR, *supra* note 49, at 388 (1982); see also FRANK MCARDLE ET AL., *Retiree Health Benefits at the Crossroads*, KAISER FAMILY FOUND. 1 fig.1 (2014), <https://kaiserfamilyfoundation.files.wordpress.com/2014/04/8576-retiree-health-benefits-at-the-crossroads.pdf> (illustrating a decline from 68% of large firms offering retiree health benefits in 1988 to 28% in 2013).

306 See NAT’L ALLIANCE, CAREGIVING, *supra* note 80, at 18.

A middle-aged man with a wife and no kids has bone-marrow cancer. His medical care, including chemotherapy and a bone-marrow transplant, may continue for years. (Midlife-Disruption Scenario)

An elderly widower with two adult children, a daughter and a son, has a stroke. He had been living independently yet modestly among a community of close friends. Now he needs help with basic activities, like showering, voiding, and preparing his food. (Aging Parent Scenario)

It is likely that the parents, the wife, and the daughter (less likely but possibly the son or a close family friend) will take on responsibility for caregiving in these cases. They are the next friends, responsible in practice, even if not required by law, for the long-term care and wellbeing of another. Are the burdens each faces similar next-friend risks, or is there something fundamentally different about these situations that warrants treating them differently?

Above, I offered one definition of risk as a probabilistic harm. To some, the Aging Parent Scenario might seem more an inevitability. It is more common that someone would need to care for a parent than for a spouse, sibling, child, or friend with serious illness and disability.³⁰⁷ One implication might be that adult children should thus expect and plan for parental care. Even though more common, about one-half of people never need long-term care and, among those who need care, the amount of care needed is highly variable, ranging from very little to years of intensive care.³⁰⁸ Thus, even for adult children, it would be difficult to know what level of parental care to anticipate.

Conversely, some might have an intuition against seeing the Lifelong Care and Midlife Disruption scenarios as cases of next-friend risk. Perhaps people take a gamble when they have a child or get married, and the harms that result are not morally arbitrary. Ronald Dworkin called non-arbitrary harm the result of “option luck,” as contrasted with “brute luck.”³⁰⁹ The principle that justice demands less for harms that result from option luck has

³⁰⁷ See *supra* note 174.

³⁰⁸ LEORA FRIEDBERG ET AL., CTR. FOR RET. RESEARCH AT BOS. COLL., NEW EVIDENCE ON THE RISK OF REQUIRING LONG-TERM CARE 4, 23-24 (2014), http://ctr.bc.edu/wp-content/uploads/2014/11/wp_2014-12.pdf (summarizing existing research and providing new estimates that indicate more people will need long-term care than earlier estimates suggest but of a shorter average duration).

³⁰⁹ RONALD DWORKIN, SOVEREIGN VIRTUE 73 (2000). *But cf.* Peter Vallentyne, *Brute Luck, Option Luck, and Equality of Initial Opportunities*, 112 ETHICS 529, 532-37 (2002) (arguing that brute luck might be easier to define in theory than in application).

been called “choice-sensitivity.”³¹⁰ Kenneth Abraham describes that “the degree to which a risk is controllable and the degree to which the activity producing it is socially optional, would form the basis of an egalitarian standard of fair risk distribution in insurance.”³¹¹ Put simply, people should bear the costs of their own choices.

Someone’s choices can undeniably increase the likelihood of becoming responsible for someone else. Some people explicitly promise to care for life partners in sickness, as well as in health. Likewise, most people choose whether to have children, knowing that raising children is a risky endeavor in ways that both can and cannot be anticipated. At the most basic level, most of us know (or should know) that there is some potential for extraordinary levels of responsibility for another when entering into a relationship. Perhaps parents, spouses, and friends have assumed the risk of such responsibility when they enter into relationships, in a way that children, grandchildren, and siblings have not.³¹²

Yet, these distinctions between those relationships we choose and those we are born into are shaky. Reasonable people may actually not understand the extent of responsibility they could bear for another when they marry or have a child. Most people underestimate the chance that someone they love will become disabled or ill and need care, especially when it is a distant possibility.³¹³ Many people assume that their insurance—public or private—will cover long-term care, when in most cases it does not.³¹⁴ Additionally, as discussed above, the nature of care for a person with a disability is quickly becoming more medically intensive over time than most people could imagine. Thus, most people marry or have children with no concept of the potential responsibility they face if a loved one suffers from chronic illness or disability.

³¹⁰ See, e.g., G.A. Cohen, *On the Currency of Egalitarian Justice*, 99 ETHICS 906, 916 (1989) (proposing an “equal access advantage” theory, wherein involuntary disadvantages—those beyond the actor’s control—merit compensation, while disadvantages incurred voluntarily by the actor do not). But see Shiffrin, *supra* note 301. (challenging the egalitarian emphasis on choice sensitivity as a problem for individual freedom). Perceptions of control have been important historically for social insurance. Advocates built support for workers’ compensation by showing statistically that most workplace injuries were not a worker’s fault. See WITT, *supra* note 24, at 142-43.

³¹¹ ABRAHAM, *supra* note 265, at 27.

³¹² See Mary Anne Case, *How High the Apple Pie: A Few Troubling Questions About Where, Why, and How the Burden of Care for Children Should Be Shifted*, 76 CHI-KENT L. REV. 1753, 1758 (2001) (arguing against employment- or state-based parental benefits because they cause the childless to subsidize those who have children, which often benefits the male worker).

³¹³ See Brown & Finkelstein, *supra* note 33, at 131 (explaining why research suggests that limited knowledge or bounded rationality might limit purchase of private long-term care insurance).

³¹⁴ See Brown et al., *supra* note 35, at 1298.

Assume for a moment, however, that people did fully contemplate this potential responsibility and still engage voluntarily in relationships. There are reasons why even in this case it might not make sense for them to fully internalize the costs. The state often helps people whose choices increase their risk of harm in order to protect such choices or to promote other important values.³¹⁵ For example, our courts invalidate indemnification clauses in agreements for participation in sports or dangerous activities³¹⁶ and agreements where patients contract away the right to sue in return for medical care,³¹⁷ when it seems unjust for individuals to bear the costs of harm. Disaster relief efforts bail out people who built their homes in flood plains, on earthquake fault lines, or along Tornado Alley because asking them to bear the costs individually would be devastating.

Social insurance often mitigates harms, even when individual agency may increase the risk. Medicare covers medical harms for people who are sicker because they did not care for their bodies in the first sixty-five years of their life. Social Security does not differentiate between those people who failed to save and those who succeeded.

François Ewald describes the paradigm of social solidarity underlying social insurance as “not based on fault but on risk.”³¹⁸ What he means is that it is less important to diagnose *ex post* whether an individual intensified the possibility of harm she suffers. The more consequential question is whether we want individuals to bear the full cost of obligations simply because they derive in part from their own actions. We might in fact *not* want people to bear the full costs of extraordinary obligation for loved ones because it could dissuade kinship relationships. By not requiring people to bear the full cost of such choices, social insurance protects the activity in which they participate—in this case getting married or having children.

Even among choice-sensitive egalitarians, there is disagreement about what should be attributed to choice.³¹⁹ Individual decisions to partner and to have children are in most cases voluntary. But in aggregate, they are not. Imagine a society where no one developed long-lasting relationships, or no one had children. It would be a dismal and short-lived society. When considered from a collective, rather than individual, perspective, entering into kinship relationships can be seen as the kind of non-optional social activity

315 Shiffrin, *supra* note 301, at 275-84 (providing examples of “accommodation practices,” where we absorb costs of others’ voluntary behavior, including exemptions to the draft and exempting some people from working on religious holidays).

316 *E.g.*, *Hanks v. Powder Ridge Rest. Corp.*, 885 A.2d 734, 742 (Conn. 2005).

317 *E.g.*, *Tunkl v. Regents of the Univ. of Cal.*, 383 P.2d 441, 448-49 (Cal. 1963) (en banc).

318 Ewald, *supra* note 24, at 277.

319 Shiffrin, *supra* note 301, at 272.

that Abraham contends meets the egalitarian standards for risk spreading,³²⁰ or as deserving because such relationships are something “profoundly good for society.”³²¹

So far, I have discussed cases where someone increases next-friend risk simply by engaging in a relationship where she makes it more likely that she will take responsibility for another’s unpredictable harm. A more extreme but less common example is when someone acts in a way that increases the likelihood of someone else becoming ill or disabled. In other words, her choices increase the risk that someone for whom she is responsible would need long-term care, not just the risk that she will be responsible for it if it occurs due to random misfortune. Consider, for example, a pregnant woman whose actions increase the likelihood she will have a child with birth defects or a couple who proceeds with a pregnancy after a genetic test confirms that their baby has Trisomy 18 (Edwards syndrome)—a chromosomal abnormality that results in a child, if born alive, living a short life with intensive caregiving needs.³²²

Sometimes insurance carves out these types of situations under the label of “moral hazard,” and affirms that people should have to pay for such harms themselves. But even in these more extreme situations such exclusions might be unjust. With respect to the first example, public health studies show that certain unhealthy behaviors are shaped strongly by factors outside of an individual’s control, such as biology, psychology, or social environment.³²³ On the second, for some people, continuing a pregnancy to full-term is not a choice at all. Requiring these individuals to shoulder the full cost of a child born with a disability would, in the first, compound socioeconomic inequities and, in the second, force people to choose between their moral beliefs and their basic security.³²⁴

There is no simple, principled definition of which relationships generate next-friend risk worthy of social insurance protection. Decisions about whether such relationships are in or out are informed by moral judgment about

320 ABRAHAM, *supra* note 265, at 27.

321 Simon, *supra* note 23, at 135.

322 See, e.g., *What Is Trisomy 18?*, TRISOMY 18 FOUND. (2016), <http://www.trisomy18.org/what-is-trisomy-18>.

323 E.g., Neil Pearce & George Davey Smith, *Is Social Capital the Key to Inequalities in Health?*, 93 AM. J. PUB. HEALTH 122, 125 (2003) (describing that health is related to social factors because of “the influence of social cohesion on health-related behaviors”); see also S.A. Reijneveld, *The Impact of Individual and Area Characteristics on Urban Socioeconomic Differences in Health and Smoking*, 27 INT’L J. EPIDEMIOLOGY 33, 35, 38 (1998) (finding that poor health behaviors in impoverished areas are due overwhelmingly to individuals’ low socioeconomic status).

324 See Shiffrin, *supra* note 301, at 276 (describing how it is common to accommodate religious practices).

when caregiving should remain a private obligation and when it is worthy of collective support.

2. *Distinguishing Risk from Routine*

A second challenge is to identify what responsibilities signal that someone has experienced next-friend risk. This question demands reevaluation of what we expect from individuals and what exceeds expectations. All relationships come with responsibility. In some cases, obligations seem more routine and in others, extraordinary. For example, a daughter who grocery shops for her father and checks in on him briefly a few times a week might ensure his wellbeing with little effort. Most people would see this level of engagement as routine. Yet, if he needs eight hours of care a day and that care includes help with feeding and bathing and going to the bathroom, it seems less routine. Feeding children, bathing them, and getting them to bed are routine parts of the day for many people. Yet, around-the-clock care for a child with a serious disability or feeding, bathing, and transferring a fifty-year-old spouse into a bed are of a different nature.

What is difficult is where to draw the line between these two extremes. Some people have children who are easy to care for, and others have children who, for any number of reasons, require a much greater investment of time, energy, and, perhaps, angst. Relationships ebb and flow in what they demand from people. There is no clear line between routine and extraordinary responsibility.

One starting point would be to define next-friend risk by the triggering event. Next-friend risk is realized only when the care recipient has suffered from substantial illness or injury or has a disability that requires prolonged, intensive care. Benefits could be defined based on the disability, injury, or illness that triggered a need for care. This categorical approach is, admittedly, imprecise. A mother might engage in the exact same activities for a child without a disability as she would for one with a disability and have those activities be insurable only in the latter case. It also does not recognize the way that chronic disease evolves.³²⁵ This approach trades off nuance for administrability and, because of the latter advantage, is often the standard used in long-term care insurance benefit determinations in countries that insure long-term care.³²⁶

325 Montgomery et al., *supra* note 176, at 23 (“Initially, the care needs of the elder may be relatively small and the corresponding care tasks may represent only minimal extensions of the familial role relationship [O]ver time, the caregiving activities transform the initial mother-daughter relationship into a *caregiving* relationship.”)

326 WIENER ET AL., *supra* note 291, at 9.

Alternatively, next-friend risk could be defined in a more bottom-up way, based on the number of hours a next-friend spends in “qualifying” long-term care activities, such as helping with Activities of Daily Living. This approach is more difficult administratively, but provides a more accurate way to capture the real levels of obligation. Policies could set a baseline of care that someone would have to provide before being considered at risk—a deductible paid in dollars or hours before indemnification begins. A well-designed deductible would reduce concerns of moral hazard and reveal who are devoted next friends, because someone would have to show a level of commitment before being able to qualify for benefits.³²⁷

Defining when someone has experienced next-friend risk thus requires both determining what type of activity and what extent of activity qualifies, as well as what share, if any, should remain private obligation. Definitions that include more activities shift more responsibility away from an individual and to the collective. Conversely, carving out more activities preserves private obligation. Any method for making such decisions involves tradeoffs between precision and administrability and some arbitrariness.

3. *Does Financial Status Quo Matter?*

Should risk of harm be contingent on financial status quo? In other words, is the risk of harm merely that a next friend has to use resources, measured in time or money, to support another’s long-term care, or does risk arise only when she has to use resources that she does not have to spare?

For example, in the Aging Parent Scenario, if the daughter is wealthy, she might pay for professional care without risking her family’s financial security.³²⁸ The same is true for the parents of the daughter with autism in the Lifelong Care Scenario. Perhaps they do not experience next-friend risk if they can easily afford to enroll her in a special school and to create a trust fund for her care after they die. Using state funds to support care in these cases might be unnecessary or undesirable.

Yet, a means-based definition of risk does not capture the many ways that responsibility for another can pose burdens. Even if a next friend is wealthy, if she takes on responsibility for another, she will experience costs, both financial and nonmonetary. Requiring her to deplete her own savings reinforces a system where private obligation is primary and the state’s role is

³²⁷ It might also lead to a consolidation of care because, with multiple caregivers, it is possible that no one would exceed the deductible.

³²⁸ The same might be said if she has a lot of free time and provides care directly. Does her temporal status quo matter? I previously addressed this question in more detail, *see supra* Section II.C, but just note that the same analysis could apply with respect to time, as respect to money, here.

secondary.³²⁹ Making eligibility contingent on wealth also devalues the nonmonetary costs she faces.

Attempts to define risk based on a next friend's wealth may also be futile. As noted above, few people have the resources necessary to pay for any prolonged period of long-term care—one reason why most next friends provide it in kind. Trying to isolate the few who do have such resources would require significant administrative effort with little payoff. Furthermore, if care recipients can choose any next friend, they could just designate a poor family member. Means tests would dissuade people who are in more stable circumstances from taking on the role of next friend if they cannot claim state support but a sibling or friend in a more precarious position could. The end result might be suboptimal care arrangements.

Defining risk as contingent on a next friend's financial resources would replicate current inequities in financing for long-term care. Poor next friends, who qualify for benefits, could use the benefits to choose to arrange for or to provide care. Wealthy next friends would self insure and have the same choice. But middle-income next friends would neither qualify for benefits nor have money to pay for care, leaving them in the same position many are in today: providing care because no other option is available.

Another approach, in a classic model of social insurance, defines harm based on an *ex ante*, population-based view. Not knowing what any one individual's lot in life will be, social insurance is designed to protect everyone from "common economic risks in a changing world."³³⁰ Those who end up less in need of such protections because of a good lot in life are not expunged from the program *ex post*. For example, Medicare pays for medical care for nearly all Americans over age sixty-five, regardless of wealth level, protecting against harm from poor health in retirement. Likewise, Social Security pays benefits to all eligible retirees, regardless of private savings.

A universal approach would, in effect, define next-friend risk simply as taking responsibility for the long-term care of another. Avoiding categorical inquiry would have all of the benefits that accrue to other universal social insurance programs. Social Security and Medicare—the two social insurance programs with near universal contribution and benefits—endure as among the most popular U.S. government programs.³³¹ As expressed in a recent book on social insurance: "Covering most people at risk and treating everyone equally

329 See Zatz, *supra* note 302, at 580 (reasoning that expecting family or friends to pay for another in need can be seen as the "state . . . exploiting their generosity").

330 MARMOR ET AL., *supra* note 24, at 217.

331 *Id.* at 219 ("[B]ecause everyone is both a contributor and a potential beneficiary, the politics of social insurance tends to be of the "us-us" rather than the "us-them" form.")

as risk bearers increases the sense of social insurance's fairness."³³² Nearly eighty percent of Americans think these programs have benefitted the United States and a majority would not reduce current benefit levels to reduce the deficit or taxes.³³³

Means-testing, in contrast, is solidarity-diminishing because it draws a line between the haves, who are self-sufficient, and the have-nots, who are not.³³⁴ Creating universal benefits can avoid such stratification. As one expert describes, it enhances the "pedigree of cultural respectability" of a program by not requiring "questions about morally freighted matters such as family income and assets, household composition, or individual work effort."³³⁵

Yet, a universal approach can redistribute resources from categories of people who are low risk to those who are high risk in a way that will, in some cases, be regressive. For example, if people with no siblings are at higher risk of caring for a parent and also more likely to be higher income, they might be subsidized by people who are on average lower income. Regressivity can be lessened by progressive financing. If the higher-income child contributed to the program more through higher tax rates throughout her lifetime, she could draw benefits without necessarily being subsidized by lower-income others.³³⁶ Social Security and Medicare are both structured in this way.

A separate question is whether next-friend risk can exist at all when the *care recipient* has financial resources to pay for care.³³⁷ When a person with a disability or illness can finance his own care, his family member, in theory, faces less responsibility. For example, if the father in the Parent Scenario were wealthy, he could pay for someone to provide his care. Or he could ask his daughter to provide the care and compensate her.³³⁸ This issue highlights the relational aspect of long-term care risk. Social insurance benefits for the daughter of a wealthy man might effectively serve to preserve her inheritance. Some might gauge use of collective resources in this way as less just or lower priority. Others might see her inheritance as part of what she has to lose from next-friend risk.

³³² *Id.*

³³³ *Id.* at 222.

³³⁴ GÖSTA ESPING-ANDERSEN, *THE THREE WORLDS OF WELFARE CAPITALISM* 63-64 (1990).

³³⁵ MARMOR ET AL., *supra* note 24, at 219.

³³⁶ See Louis Kaplow & Steven Shavell, *Why the Legal System Is Less Efficient Than the Income Tax in Redistributing Income*, 23 J. LEGAL STUD. 667, 674-75 (1994).

³³⁷ This question is relevant to care for a parent or friend but would not apply in most cases where the care recipient is a child or a spouse.

³³⁸ Of course, such a bargain is complex and often results in broken promises. See HARTOG, *supra* note 29.

These difficult boundary questions are a core part of any social insurance design. It is necessary first to quantify a harm someone has experienced and then, second, to decide who should pay that price.

E. Objections to Insuring Next-Friend Risk

Any expansion of social insurance is highly contested—an understatement in light of the fact that, years after its passage, the ACA remains under constant attack.³³⁹ The standard objections involve questioning the proper role of the state, administrability, and affordability. Policies where family members can be paid for caregiving trigger heightened moral hazard and fraud objections—objections that have the rhetorical power to stop policies in their tracks. Each of these concerns, discussed in turn herein, can inform better policy design, but none is good reason to choose not to better insure next-friend risk.

An increased state role in long-term care can threaten the strong tradition and social norms of family care. The state's entry into this domestic sphere sparks concerns of commodification of family caregiving, which could mean a number of different things.³⁴⁰ Sometimes, commodification objections are mere pretext for preserving the current, gendered system of caregiving or are a thinly veiled way of suggesting that care work is not something public resources should compensate. That is the very view this Article aims to challenge. A more complex version of a commodification critique is that paying for family care would diminish its value because of the “corrosive tendency of markets.”³⁴¹ This view is well-intentioned, motivated by the desire to protect goodness in the connection between loved ones. Yet it is based on a fallacy that caregiving and economic activity exist independently. Caregiving has long had an implicit and explicit price, both within and outside of the family structure.³⁴² In other words, the worlds of money and love are already deeply blurred.

339 See Deirdre Walsh, *House Sends Obamacare Repeal Bill to the White House*, CNN (Jan. 6, 2016), <http://www.cnn.com/2016/01/06/politics/house-obamacare-repeal-planned-parenthood> (describing the most recent of more than sixty votes to repeal all or part of the law).

340 See Deborah Stone, *For Love Nor Money: The Commodification of Care*, in *RETHINKING COMMODIFICATION* 271 (Martha M. Ertman & Joan C. Williams eds., 2005).

341 MICHAEL J. SANDEL, *WHAT MONEY CAN'T BUY: THE MORAL LIMITS OF MARKETS* 9 (2012); see also Elizabeth S. Anderson, *Is Women's Labor a Commodity?*, 19 PHIL. & PUB. AFF. 71, 80 (1990) (considering the special case of surrogacy and the risk of reducing women from “persons worthy of respect” to “objects of mere use”); Viviana A. Zelizer, *Human Values and the Market: The Case of Life Insurance and Death in 19th Century America*, 84 AM. J. SOC. 591 (examining concerns of commodification of death with the introduction of life insurance and the gradual diminishing of such concerns).

342 See HARTOG, *supra* note 29; Alstott, *supra* note 141; Joan C. Williams & Viviana A.

There are, however, some aspects of what family and friends and, also, paid caregivers provide that could never be priced in dollar terms.³⁴³ But paying for the aspects that can be valued—the heavy lifting of long-term care, so to speak—need not diminish or crowd out the intimate aspects of care. In fact, empirically it does not. Studies show exactly the opposite: even paid caregivers show great affection for the people for whom they care.³⁴⁴ Furthermore, even when families hire paid caregivers, family members continue to spend significant time caring but focus instead on the tasks that they are better suited than a formal caregiver at doing.³⁴⁵

A related critique is that state involvement requires an invasion of private, family space. It is true that the availability of benefits requires the state to determine eligibility, and the receipt of money necessarily invites monitoring. A universal social insurance program with categorical benefits would minimize the invasiveness of both efforts. Some research suggests that even informal caregivers who face significant burden are skeptical of state involvement, but this study also shows that the availability of social insurance relief can shift both their roles and their perspectives.³⁴⁶ In other words, the privacy concerns seem less acute when a family caregiver experiences the benefits of state support.

Another objection to any expansion of social insurance is that it will crowd out private insurance solutions or private savings, which studies confirm does occur to some degree.³⁴⁷ The obvious response in the case of next-friend risk is that even without public insurance, private insurance solutions have failed. The level of private savings that a next friend would need to have to effectively self-insure is impossible for nearly everyone, even if they saved aggressively. Furthermore, this concern presumes that private insurance or saving is the best first option and that state responsibility should only be a last resort—the very assumption this Article challenges.

Zelizer, *To Commodify or Not To Commodify: That is Not the Question*, in *RETHINKING COMMODIFICATION*, *supra* note 340, 362, 364-65.

343 See Margaret Jane Radin, *Market Inalienability*, 100 HARV. L. REV. 1849, 1885 (1987).

344 See Stone, *supra* note 340, at 275-77 (discussing studies).

345 STONE, *supra* note 168, at 20-21. But see Susan L. Ettner, *The Effect of the Medicaid Home Care Benefit on Long-term Care Choices of the Elderly*, 32 ECON. INQUIRY 103, 123 (1994) (showing substitution effects of a greater degree than in other studies); Norma B. Coe et al., *Family Spillovers of Long-Term Care Insurance* 18 (Nat'l Bureau of Econ. Research, Working Paper No. 21483, 2015), http://www.terry.uga.edu/media/events/documents/Norma_Coe.pdf (showing that private long-term care insurance lowers informal caregiving and the likelihood of a child living with a parent).

346 Levitsky, *supra* note 169, at 564.

347 See David M. Cutler & Jonathan Gruber, *Does Public Insurance Crowd Out Private Insurance?*, 111 Q.J. ECON. 391, 391 n.1 (1996).

That all said, private insurance options could be developed over time and integrated with public solutions to the degree desired. In fact, if private insurance policies were marketed to next friends to mitigate the risk they face, it might prove more saleable. Some of the bias that thwarts people from buying long-term care policies for themselves might not deter children from insuring against the risk of caring for their parents or future parents from insuring against the risk of a child with a disability. And, according to one study, if private policies included benefits to pay family members for care, there would be greater purchase of them by people who now opt out because they prefer family care over formal care.³⁴⁸ Social insurance policies could continue to include incentives for the purchase of private long-term care policies, as in the long-term care partnerships.³⁴⁹

Moral hazard and fraud are simultaneously sources of genuine concern and red herrings. As Jonathan Simon has written, “The perception that fraud is rampant in welfare and social insurance systems has helped to de-legitimize broad, entitlement-based risk spreading programs. Indeed . . . moral hazard has become a block on any substantial expansion of social insurance in recent decades.”³⁵⁰ Moral hazard is the idea that when people are insured, they have reduced incentive to avoid losses. Moral hazard can be an ex ante failure to prevent losses (i.e., carelessness when insured) or an ex post failure to mitigate losses as inexpensively as possible (i.e., malingering).³⁵¹ Ex ante moral hazard—the idea that people will fail to prevent harm—is inapt in this context. The risk of harm is only triggered by the disability or illness of a loved one, circumstances that people avoid for independent reasons, even if insured. The more pertinent concern is that social insurance will lead to overuse of benefits. In other words, the number of people living with and caring for someone else will skyrocket in response to the availability of insurance benefits.

This so-called woodwork effect might capture two different things. It might simply mean that more people are getting the necessary care that they were not before. Meeting unmet demand in this way is what Deborah Stone

³⁴⁸ See Mommaerts, *supra* note 39.

³⁴⁹ See, e.g., Jamie P. Hopkins et al., *Leveraging Filial Support Laws Under the State Partnership Programs To Encourage Long-Term Care Insurance*, 20 WIDENER L. REV. 165, 195 (2014) (arguing for increased enforcement of filial support laws as a “stick” to incentivize private insurance purchase by increasing personal liability); Haizhen Lin & Jeffrey T. Prince, *Determinants of Private Long-Term Care Insurance Purchase in Response to the Partnership Program*, 51 HEALTH SERVS. RES. 687, 699-700 (2016) (finding that efforts at program awareness and financial literacy may increase program success). For discussion of these programs and their shortcomings, see *supra* note 44 and accompanying text.

³⁵⁰ Simon, *supra* note 23, at 131.

³⁵¹ See Tom Baker, *On the Genealogy of Moral Hazard*, 75 TEX. L. REV. 237, 270 (1996).

has called a “moral opportunity” and is the very purpose of social welfare programs.³⁵² It could also mean that people are exaggerating a need for care, if someone could get by on her own but will take help if a family member can get cash benefits to provide the assistance. This possibility is harder to avoid, but can be lessened through well-designed criteria for eligibility based on a disability determination. Other countries with social insurance for long-term care have developed systems where case workers or medical professionals measure and categorize levels of disability, which have worked reasonably well.³⁵³

Avoiding moral hazard informs the design of any social insurance program. As Anne Alstott has written, “Moral hazard permeates every form of insurance, and . . . there are a host of tools for managing it, including copayments, categorical eligibility, delayed benefits, limited benefits, self-financing, and so on.”³⁵⁴ With respect to long-term care, a deductible could reduce moral hazard. As suggested above, policies could set a number of hours of care that someone would have to provide or arrange and pay for before she would qualify for benefits. Even if it is a real concern, empirical evidence of long-term care social insurance that pays family members cash benefits suggests that such concerns may be overstated.³⁵⁵

Fraud may be a more challenging problem. People might misrepresent disability if they can get cash benefits for family. Or next friends might claim benefits and not provide care. Fraud enforcement with personal care services is particularly difficult because the services are diffuse in individual homes and hard to monitor. The Office of the Inspector General of the Department of Health and Human Services has already made a special effort to detect fraud in home-based personal care services under Medicaid.³⁵⁶ Medical eligibility determinations can be used to root out false claims. And high penalties for fraudulent claims can be used as a deterrent. Even though there would undoubtedly be some problems with fraud, evaluation of demonstration projects, where benefits can be used to pay family for care, have also found surprisingly few cases of fraudulent use of the benefits.³⁵⁷

³⁵² Deborah Stone, *Beyond Moral Hazard: Insurance as Moral Opportunity*, 6 CONN. INS. L.J. 11, 14-15 (1999).

³⁵³ See WIENER ET AL., *supra* note 291, at 8.

³⁵⁴ Alstott, *supra* note 141, at 30.

³⁵⁵ See Joshua M. Wiener & Alison Evans Cuellar, *Public and Private Responsibilities: Home- and Community-Based Services in the United Kingdom and Germany*, 11 J. AGING & HEALTH 417, 423 (1999) (explaining that in the German program, the number of enrollees was nearly the number estimated and the greater concern is underreporting of disability).

³⁵⁶ Office of Inspector General, *Spotlight on . . . Medicaid Personal Care Services*, U.S. DEP'T HEALTH & HUMAN SERVS. (June 7, 2011), <https://oig.hhs.gov/newsroom/spotlight/2012/portfolio01.asp>.

³⁵⁷ See ROBERT WOOD JOHNSON FOUND., CASH & COUNSELING PROGRAM RESULTS (2013), http://www.rwjf.org/content/dam/farm/reports/program_results_reports/2015/rwjf406468.

Concerns about quality of care when provided by family or friends is a particularly American preoccupation. Other countries with long-term care policies that offer cash benefits for family to provide care believe that, in general, people are likely to get *better* care from family than from formal caregivers.³⁵⁸ Results from the Cash and Counseling Demonstration project in the United States revealed fewer cases of abuse and neglect and fewer unmet needs among beneficiaries who used a cash benefit compared to control group members.³⁵⁹ There would of course be some problems with poor quality care at the hands of friends or family, but it may prove no worse—and possibly better—than in formal care settings. Further, these next friends are many of the same people providing unpaid care today. Compensating them for their work would be unlikely to reduce the quality of their caregiving.

Finally, any comprehensive solution would be very expensive—a fact which undoubtedly influences many scholars' pragmatic focus on piecemeal solutions. Total paid long-term care was just over \$220 billion in 2011, excluding Medicare post-acute care.³⁶⁰ The aforementioned estimate of replacement cost of family caregiving is \$470 billion, which would triple current spending, and is only a partial account of long-term care since it only considers care for adults.³⁶¹ This increased cost is a genuine hurdle.

Current policy, however, has simply obscured the fact that individuals shoulder those costs privately, as an invisible copayment, and has enabled political inaction. The United States spends relatively less on long-term care than other developed countries do, even as it spends more on nearly every other category of health care.³⁶² Accounting for next-friend risk makes it harder to continue down this path. If the Congressional Budget Office were to include the over half-trillion dollars in care provided by informal caregivers as a cost of current policies, it would hamstring these policies that are biased toward informal caregiving.³⁶³ Legal myopia has saved the government an estimated half-trillion dollars a year in direct costs. These costs are not avoided. They are simply borne off budget and disproportionately by people less able to bear them.

358 See WIENER ET AL., *supra* note 291, at 19-20.

359 Barbara Lepidus Carlson et al., *Effects of Cash and Counseling on Personal Care and Well-Being*, 42 HEALTH SERVS RES. 467, 476-79 (2007).

360 O'Shaughnessy, *supra* note 9, at 3.

361 Reinhard et al., *supra* note 26, at 3.

362 MCKINSEY CTR. FOR U.S. HEALTH SYS. REFORM, *supra* note 262, at 9.

363 Although the Congressional Budget Office generally does not consider opportunity costs, it does consider the macroeconomic second-order or "dynamic" effects of policies in its budgetary analysis. See Keith Hall, *Answers to Questions About Dynamic Analysis*, CONG. BUDGET OFF. (July 1, 2015), <https://www.cbo.gov/publication/50357>.

* * *

In sum, the real costs of our current system and the insecurity and inequities it generates demand recognizing next-friend risk and considering it on par with care-recipient risk. In part, social policies have prioritized care-recipient risk because of the immediacy of the need, the vulnerability of the recipients, and the dire consequences of failing to meet their needs. But next-friend risk is creating deep and long-lasting harm. This harm is easier to ignore but no less important of a target for social policy. Although we should not neglect the short-term needs of the disabled and sick, we should no more neglect the wellbeing and security of their next friends.

Any major social problem seems too big to solve until society recognizes that the costs of not solving it are also untenable. Many other countries—including Japan, Germany, and the Netherlands, as discussed below—have overcome objections and created universal long-term care social insurance systems. These systems are expensive, and these countries certainly revisit the costs on a regular basis. Yet, they each (and others as well) have decided that long-term care is an important social priority and worth an investment of social resources.

IV. A BRIEF SKETCH OF POLICY OPTIONS

The primary goal of this Article is to introduce the concept of next-friend risk and to make the case for considering it as a social policy priority. I leave for later the development of policy details. Nonetheless, this Part offers a brief sketch of several different possible approaches to illustrate how policies—both comprehensive and incremental—can be designed in ways more sensitive to next-friend risk.

One primary goal would be to create financing and institutional structures for long-term care that enable a smoother toggle between paying for care and providing care, as described above. Policies must have a toggle in structure and support processes and institutions that empower next friends to actually choose between options. Section IV.A illustrates how a comprehensive social insurance program could better mitigate next-friend risk. Yet, incremental changes that build on existing social welfare programs could also make a significant difference, as discussed in Section IV.B.

A. Envisioning Next-Friend Social Insurance

1. The Basic Concept

A universal long-term care social insurance program could be designed with the explicit goal of mitigating both next-friend and care-recipient risk. The specific contours could take many forms. The basic idea would be that

someone who has a qualifying disability would designate a next-friend, who would then receive benefits that could be used to pay for or provide care. It could be designed to supplement what Medicaid does now for care recipients or to replace it entirely. It could be created from the ground up or expand the scope and size of existing programs that are sensitive to next-friend risk, such as the Veterans Administration family caregiving program or Cash and Counseling participant-directed programs, discussed below. Others have offered proposals for universal long-term care insurance.³⁶⁴ Here, I consider specifically what elements such social insurance would need to include to be sensitive to next-friend risk and how it might differ from policies that focus narrowly on care-recipient risk.

Eligibility would be based on both the care recipient and next friend. The first step would be determination of qualifying disability or illness, based on a care recipient's condition, as with Medicaid and Medicare post-acute care now. A second step would be to identify an eligible next friend, which could be based on whom a care-recipient or her legal guardian chooses. Eligibility rules could categorically limit next friends to close relatives, as the Family and Medical Leave Act of 1993 (FMLA) does for its guarantee of twelve weeks of unpaid, job-protected leave for family care.³⁶⁵ But a more flexible definition would better reflect the existing picture of informal care, as an African saying recognizes: "The one you are left with is your relation."³⁶⁶

364 Recent proposals for universal long-term care insurance include, for example, JUDY FEDER ET AL., GEORGETOWN UNIV. LONG-TERM CARE FINANCING PROJECT, LONG-TERM CARE FINANCING: POLICY OPTIONS FOR THE FUTURE (2007), <https://georgetown.box.com/shared/static/mhdbkd4vtklps9ntkskc.pdf>; INST. OF MED. & NAT'L RESEARCH COUNCIL OF THE NAT'L ACADEMIES, FINANCING LONG-TERM SERVICES AND SUPPORTS FOR INDIVIDUALS WITH DISABILITIES AND OLDER ADULTS: WORKSHOP SUMMARY (2013), <http://www.nap.edu/read/18538/chapter/1>; UNIVERSAL COVERAGE OF LONG-TERM CARE IN THE UNITED STATES: CAN WE GET THERE FROM HERE? (Douglas Wolf & Nancy Folbre, eds., 2012); Laphonza Butler et al., Long-Term Care Comm'n, *A Comprehensive Approach to Long-Term Services and Supports* (Sept. 23, 2013), <http://www.medicareadvocacy.org/wp-content/uploads/2013/10/LTCCAlternativeReport.pdf> (dissenting report from Commission on Long-Term Care's September 30, 2013 Report to the Congress); Melissa M. Favreault et al., *Financing Long-Term Services and Supports: Options Reflects Trade-Offs for Older Americans and Federal Spending*, 34 HEALTH AFF. 1 (2015); Lee Goldberg & G. Lawrence Atkins, *Social Insurance: A Critical Base for Financing Long-Term Services and Supports*, SCAN FOUND. (2013), http://www.thescanfoundation.org/sites/default/files/ltc_financing.social.insurance.goldberg.3.20.13.pdf; and Anne Tumlinson et al., *Insuring Americans for Long-Term Care: Challenges and Limitations of Voluntary Insurance*, AVALERE HEALTH (2013), http://avalere.com/research/docs/20130320_Avalere_RTI_Scan_LTI.pdf.

365 29 U.S.C. § 2612(a)(1)(C) (2012) (reserving job-protected leave for parents, children, and spouses).

366 WORLD HEALTH ORG., *supra* note 277, at 11; see also Nancy Knauer, *LGBT Older Adults: Chosen Family and Caregiving*, 31 J.L. & RELIGION (forthcoming 2016),

Program rules might limit the caregiving any one individual can be paid to do or the number of people for whom she could be paid to coordinate in-kind benefits.

The process of having to designate a next friend offers the collateral benefit of prompting more transparent and deliberate decisions about long-term care. Naming a next friend would make clear who is responsible for helping a care recipient with care management decisions, akin to naming a health care proxy. If benefits were vested in or controlled in part by the next friend, it could encourage a care recipient to initiate explicit conversations about what kind of care he wants with his next friend, before the next friend helps him to operationalize his care.

Any individual who does not want to provide care would have greater ability to opt out. The universality of benefits, and the ability to use them interchangeably to pay for in-kind care, would bolster her bargaining power.³⁶⁷ Imagine that a mother asks her daughter to care for her in her old age. Without next-friend insurance, she may feel as if she has few options. With it, in contrast, she could accept responsibility and provide care and get paid to do so. She could accept responsibility and hire someone else to provide some or all of the care, using benefits for this in-kind assistance. Or she could decline and suggest another family member or friend instead. Such conversations would undoubtedly still be shaped by family dynamics. But the goal would be for the structure of benefits to create a more neutral baseline for conversation and for real deliberation. As in other countries' social insurance programs for long-term care, case managers could explain options, mediate disputes that arise, and monitor quality on an ongoing basis.³⁶⁸

A critique of an approach that empowers next friends in the decision process is that it erodes the autonomy that independent living movement advocates have long worked to wrest back for care recipients, by requiring them to name a next friend who has some control over how benefits are used.³⁶⁹ Care recipients, however, would retain the ultimate control through the ability to designate the next friend.³⁷⁰

http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2721451 (exploring the disproportionate reliance on non-relatives for long-term care within the aging LGBT community).

367 Cf. RHONA MAHONY, *KIDDING OURSELVES: BREADWINNING, BABIES AND BARGAINING POWER* (1996) (discussing how women can use bargaining theory to undo sexual division of labor in the home, in part based on having an income-generating position).

368 See WIENER ET AL., *supra* note 291, at 8.

369 See Batavia et al., *supra* note 48.

370 There could be an option that allows someone who wants to and is able to do so to manage his own care by designating a formal care provider to serve as the next friend. Letting someone choose to bypass friends and family altogether would still serve the ends of protecting friends and family from next-friend risk, while also meeting a care-recipient's needs and honoring his autonomy.

More importantly, the reality is that many people rely on family to help meet their long-term care needs now, and recognizing these caregiving dyads more formally in the law would be beneficial. For example, it could address problems in the Medicaid consumer-directed demonstration programs, in which care recipients can hire and fire their own provider. One criticism of these programs is that they turn care recipients into employers and put them in a position where they might mismanage their personal budgets.³⁷¹ The responsibility can be burdensome: “only a fraction of individuals with disabilities have the time, inclination, and skills to search for, hire, and train their own personal assistants. . . . Many people, disabled and nondisabled . . . find that the burdens of becoming an employer are great.”³⁷² Plus, these programs have eroded caregivers’ job benefits and labor protections because they treat each care recipient as an individual employer.³⁷³ Taking the care recipient out of the middle so that the state directly pays the next friend or formal caregiver, once selected, avoids these problems. It may be that care recipients find that the ability to influence their care, without having to manage it or to become an employer, is even more autonomy enhancing.

Next-friend insurance could professionalize long-term care services, by more formally recognizing the work friends and family do and creating a structure for formal labor protections and job benefits. The Department of Veterans Affairs (VA) family caregiver program offers a model. It compensates family caregivers at higher rates than other programs and also addresses sources of nonmonetary harm.³⁷⁴ Family caregivers of seriously injured post-9/11 veterans can receive health insurance, mental health services, comprehensive training by Easter Seals, respite care of thirty days or more a year, and reimbursement for travel expenses when accompanying the veteran for care.³⁷⁵ These types of protections would benefit all informal and formal caregivers.

The point here is not to flesh out the full details of a new social insurance benefit but rather to highlight the most critical elements. Next friends would be formally appointed and have a voice in decisions. They would be treated as workers, if they provide care, or compensated for their time as case managers if they help to arrange care. The goals of such policies would be two-fold: to get people needed long-term care, and to enable their friends and family to help them do so without taking on excessive risk themselves.

371 See Crowley, *supra* note 95, at 16.

372 Bagenstos, *supra* note 73, at 79.

373 See Smith, *Home Sweet Home*, *supra* note 126.

374 Czaplanski, *supra* note 123, at 58.

375 *Services for Family Caregivers of Post-9/11 Veterans*, U.S. DEP’T VETERANS AFF. (Aug. 10, 2012), http://www.caregiver.va.gov/support/support_benefits.asp.

2. *Models for Next-Friend Social Insurance*

The idea of creating a social insurance program explicitly intending to benefit next friends might seem utopian, but there are already elements of this type of approach in practice in various small-scale programs, including the VA program, the consumer-directed Medicaid programs, and in the state paid leave programs in California, New Jersey, and Rhode Island, which offer benefits to pay for time spent caregiving for family or friends.³⁷⁶ Next-friend social insurance could build on these types of efforts.

It could also be based on the models of universal long-term care social insurance implemented in other countries. At the very least, the different models chosen elsewhere provide a window into policy design that is more or less sensitive to next-friend risk.

Lessons from long-term care social insurance in Japan, the Netherlands, and Germany illustrate how long-term care policy can be designed in ways more or less sensitive to next-friend risk. The long-term care policies in these three countries share many characteristics: they are all non-means tested, universal social insurance programs funded primarily by payroll taxes (and secondarily by premiums in Japan and copayments in Germany).³⁷⁷ The Dutch and German programs are for beneficiaries of all ages,³⁷⁸ while the Japanese program is for older beneficiaries.³⁷⁹ They all give beneficiaries some level of control over benefits. Yet, each has had very different results.

The Japanese program strongly discourages family care with the goal of displacing the tradition of reliance on daughters-in-law for elder care.³⁸⁰ The program was developed to address social changes similar to those in the United States that made this reliance unsustainable: fewer people are living with their children; an increased number of women are working; and people are more willing to accept outside help.³⁸¹ This program *only* pays for in-kind care; cash allowances were fought by feminists who wanted dollars to be used

376 These paid leave programs (soon to be joined by New York), part of the states' temporary disability insurance, replace a portion of salary for four to six weeks when someone takes leave from a job to care for a family member, in effect compensating someone's FMLA leave. See *Paid Family Leave*, NAT'L CONF. ST. LEGIS., (2016), <http://www.ncsl.org/research/labor-and-employment/paid-family-leave-resources.aspx>.

377 See John Creighton Campbell & Naoki Ikegami, *Japan's Radical Reform of Long-Term Care*, 37 SOC. POL'Y & ADMIN. 21 (2003) (discussing the Japanese reform); Pamela Nadash et al., *European Long-Term Care Programs: Lessons for Community Living Assistance Services and Supports?*, 47 HEALTH SERVS. RES. 309 (2012) (discussing the German and Dutch programs).

378 WIENER ET AL., *supra* note 291, at 3.

379 Campbell & Ikegami, *supra* note 377, at 22.

380 *Id.* at 22.

381 *Id.*

to grow labor supply to meet demand and to liberate daughters-in-law.³⁸² They believed that an option for cash benefits would reinforce oppressive caregiving patterns. Japan's policy design could serve as a model of a strong counterbalance to existing family care biases—a thick version of neutral policy. In effect, the choice is between paid in-kind care and unpaid informal care, putting a heavy thumb on the scale for formal care but still allowing someone who strongly values providing care (or with an insistent family member) to do so without pay.

The Dutch and German systems are more similar in design, although different in result. The Dutch program illustrates a relatively flexible toggle that has resulted in ninety percent of beneficiaries choosing in-kind home-care.³⁸³ People can choose between in-kind services or a cash “personal budget” worth seventy-five percent of the value of the in-kind benefit (the discount is explained as due to the higher administrative costs of agency-based care but creates a bias toward in-kind care).³⁸⁴ For people who choose cash, at least ninety percent of the personal budget must be spent on human assistance, paying anyone the “budget holder” chooses, including friends or family.³⁸⁵ The cash benefits are relatively more valuable than in Germany, yet most Dutch claimants still choose in-kind care.³⁸⁶

Germany's program, in contrast to both the Japanese and Dutch systems, has reinforced reliance on informal caregivers. In 1994, Germany created a compulsory, universal social insurance that is available to people with more severe disabilities (defined as in need of assistance with at least two Activities of Daily Living).³⁸⁷ Like the Dutch system, it has a toggle between in-kind services and cash benefits, but the cash benefits have a face value of only 50% of the in-kind benefit.³⁸⁸ Despite this significant discount, 80 percent of home care beneficiaries and half of all beneficiaries, including those in nursing homes, have chosen the cash benefit and continue to rely on informal caregivers.³⁸⁹

Some of the variability in results may be due to different underlying social expectations or institutions but likely not all. All three countries have long histories of reliance on family for long-term care. The rates of employment of women in the Netherlands is especially low, which, in theory,

382 *Id.* at 26-27.

383 Nadash et al., *supra* note 377, at 317-18.

384 *Id.* at 314 (discussing how benefits are targeted); WIENER ET AL., *supra* note 291, at vi.

385 Nadash et al., *supra* note 377, at 320.

386 *Id.* at 318. Both countries face shortages of formal caregivers. *Id.*

387 Wiener & Cuellar, *supra* note 355, at 421; Nadash et al., *supra* note 377, at 311-12.

388 Nadash et al., *supra* note 377, at 314.

389 *Id.* at 318.

would make the opportunity costs of providing informal care lower than in Germany; yet more people choose in-kind care.³⁹⁰

Several elements of the design of the German program have been identified as perpetuating reliance on informal caregivers. The most important is that the cash benefit can be used in any way desired and is vested in the care recipient, not the caregiver; in other words, the care recipient is given cash that the government does not require be spent on human assistance, as in the Dutch program. Experts speculate that high unemployment led some beneficiaries to opt for cash benefits but then to continue to rely on *unpaid* informal care.³⁹¹

In addition, the cash benefits, when paid to a family member, are not counted as income for tax purposes.³⁹² And although like in the Dutch program, the German family workers are not formally on the state payroll and have no formal worker protections, the German government does pay into pension, health insurance, and unemployment funds for any family caregiver who provides more than fourteen hours of care per week.³⁹³ These benefits plus tax-free income might make caregiving relatively more attractive than other paid work.

Experts surmise the German program was intentionally designed to bias family care, which had been declining as families became smaller and geographically dispersed.³⁹⁴ Consistent with conservative German “family-first” notions, one expert describes that these policies “enabl[ed] women to withdraw from the workforce.”³⁹⁵ The program has thus institutionalized reliance on family care, reinforced gender roles, and not contributed to the growth of the formal labor force for caregiving. Although the German program has a policy toggle in structure, it does not operate fluidly in practice and is likely not intended to do so.

B. Incremental Reforms

A new social insurance program is not necessary, however, to better mitigate next-friend risk. Especially in the short term, it is possible to build on current policies and demonstration projects to scale them and to make them more sensitive to next-friend risk. Some approaches would require additional funding; others might not.

³⁹⁰ *Id.*

³⁹¹ *Id.* at 318 (describing that 31% of all beneficiaries and 49% at the highest level of disability report using their benefits for their own expenses).

³⁹² *Id.*

³⁹³ *Id.*

³⁹⁴ WIENER ET AL., *supra* note 291, at 15.

³⁹⁵ Wiener & Cuellar, *supra* note 355, at 439.

1. *Filling in Medicaid's Gaps*

One possibility is to fill in Medicaid's gaps so that at least those care recipients who are eligible for Medicaid might rely less on next friends. One monumental, but potentially expensive, step would be to loosen financial eligibility criteria for long-term care benefits.³⁹⁶ Doing so would increase the number of Medicaid eligible care recipients and enhance the impact of reforms that build on Medicaid as a foundation.³⁹⁷

Another incremental step would be to require states to cover more personal care services—such as assistance with bathing, feeding, transferring, or toileting—for the existing beneficiaries who receive long-term care at home, instead of in an institutional setting. As described in Part II, many states do not have personal care services programs for adults at all,³⁹⁸ or pay for a very limited quantity.³⁹⁹ Changing these benefits from optional to mandatory in the standard state programs and requiring waiver programs to cover them at sufficient levels would prevent states from shifting long-term care into home settings but then failing to cover needed care. The lack of funding for these services in home settings not only burdens next friends, it also limits choices. When family and friends can fill in the gaps, home care remains a viable option. For others, nursing home care might be the only choice. Thus, even just increasing funding for these services could meaningfully alleviate burdens and stress for next friends, while also preserving options for care recipients (even if it left largely unaltered the current structure of long-term care).

2. *Expanding and Designing Policy Toggles in Medicaid Consumer-Directed Care Programs*

A more ambitious approach is to adapt, invest in, and build out nascent programs that allow benefits to be used more flexibly. A major trend in long-term care financing is consumer-directed programs that allow beneficiaries the ability to hire, train, supervise, and fire their home-care workers. Many of these programs are designed with a toggle, where the beneficiary can choose either in-kind benefits (formal caregivers or a nursing home) or use a cash benefit to pay a family member or friend for care.

³⁹⁶ See *supra* note 70 and accompanying text.

³⁹⁷ These types of incremental expansions of eligibility used to be routine, but following the Supreme Court's decision with regard to the ACA's Medicaid expansion in *NFIB v. Sebelius* they would likely be challenged as beyond Congress' authority. See *Nat'l Fed'n of Indep. Bus. v. Sebelius*, 132 S. Ct. 2566, 2607 (2012).

³⁹⁸ *Medicaid Benefits: Personal Care Services*, *supra* note 115.

³⁹⁹ NG. ET AL., *supra* note 94, at 12-14.

These “participant directed” programs have gained popularity following a successful demonstration called Cash and Counseling, initiated in the mid-1990s by the Robert Wood Johnson Foundation.⁴⁰⁰ Six percent of Medicaid long-term care beneficiaries are now in a participant-directed program.⁴⁰¹ The terms of these programs vary considerably state-by-state on important dimensions. For example, the majority of the programs restrict hiring a legally responsible individual (e.g., a spouse, parent, or legal guardian), which can create a bias toward hiring a formal caregiver.⁴⁰² These programs will likely continue to grow as a share of Medicaid long-term care funding and can be designed to be more sensitive to next-friend risk if doing so were a core goal.

An example of how even just one design element could create bias in how benefits are used is illustrated by the In-Home Supportive Services (IHSS) program in California. This Medicaid program is the largest program in the United States with a toggle that, in design, allows benefits to pay formal caregivers or close family members.⁴⁰³ Two-thirds of IHSS recipients receive care from a relative, and in about half of these cases, they live in the same home.⁴⁰⁴ To qualify for IHSS funding, as well as Supplemental Security Income cash benefits for the person with a disability, household income must be extremely low.⁴⁰⁵ In calculating household income, these programs disregard IHSS benefits paid to a family caregiver.⁴⁰⁶ This means the money paid to a wife to care for her husband would not disqualify him from receiving benefits, but wages from her work in a job outside the home likely would. The policy creates a strong incentive for her to provide care directly, rather than keep her job and hire someone to provide the care, even if doing so leaves her insecure in the long run. Treating her IHSS income or outside income the same—either counting both or neither—is necessary to enable the toggle to work.

400 See ROBERT WOOD JOHNSON FOUND., *supra* note 357.

401 *Facts and Figures: 2013 National Inventory Survey on Participant Direction*, NAT'L RES. CTR. FOR PARTICIPANT-DIRECTED SERVS 5 fig.2 (2014), https://nrcpds.bc.edu/downloadfile.php?filename=1411162479_NRCPDS_Facts_Figures_Final.pdf. Six percent includes over thirty percent of beneficiaries in California, which skews the national average. *Id.*

402 *Id.* at 11 (reporting that 11% of responding programs indicated that a spouse, parent, or legal guardian could be paid as a caregiver).

403 ROBERT MOLLIKA & LESLIE HENDRICKSON, HOME AND COMMUNITY-BASED LONG-TERM CARE: RECOMMENDATIONS TO IMPROVE ACCESS FOR CALIFORNIANS 17 (2009), <http://www.canhr.org/reports/HomeCommunityBasedCare2009.pdf>.

404 *Considering the State Costs and Benefits: In-Home Supportive Services Program*, CAL. LEGIS. ANALYST'S OFF. (2009), http://www.lao.ca.gov/reports/2010/ssrv/ihss/ihss_012110.aspx.

405 *IHSS Eligibility Information*, CAL. DEP'T SOC. SERVS. (2013), <http://www.cdss.ca.gov/cdssweb/PG135.htm>.

406 20 C.F.R. § 416.1161(a)(16) (2016). Under this rule, “in-kind support and maintenance” is also not deemed income. *Id.*

As participant-directed care grows in the United States, an approach sensitive to next-friend risk would consider how policies should be designed to avoid reinforcing a strong bias toward family care, as in Germany or California. The goal should be, at the very least, policies that aim for a thin version of neutrality.

3. *Investments in Infrastructure*

Investment in community-based care infrastructure and a formal labor force could enhance options in the gap between nursing home and home-based care. New models show that high-quality care can be provided in community settings, but these existing models exist as isolated experiments and mostly focus on elder care.⁴⁰⁷

One of the first programs, which combines health and personal care needs is called On Lok and was started as a health plan in San Francisco in 1971 to help an aging Asian population age at home.⁴⁰⁸ On Lok inspired a Medicare demonstration program known as the Program for All-Inclusive Care for the Elderly (PACE).⁴⁰⁹ The most intriguing part of the model is the On Lok Lifeways Centers, which they call the “hub” of the program, where participants go from one to five days a week for medical care, adult day care, and social activities, including exercise and meals.⁴¹⁰ The model has targeted low-income and frail elderly.⁴¹¹ Participants who are eligible for Medicare, Medicaid, and SSI pay nothing out of pocket; others pay a monthly fee.⁴¹² For example, people eligible only for Medicare can “top off” Medicare benefits, which enables middle-income families to afford these programs and increases

407 Some models of innovative care for children with disabilities exist as well, but are less common. For example, the Center for Discovery is a residential center for children, which offers “advanced care and treatment” of young people with “medical complexities” and autism spectrum disorders. See *What We Do*, CTR. FOR DISCOVERY (2013), <http://www.thecenterfordiscovery.org/what-we-do>.

408 *About On Lok*, ON LOK (2015), <https://www.onlok.org/about>.

409 INST. OF MED., *RETOOLING FOR AN AGING AMERICA: BUILDING THE HEALTH CARE WORKFORCE* 84-85 (2008), <http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2008/Retooling-for-an-Aging-America-Building-the-Health-Care-Workforce/RetoolingforanAgingAmericaBuildingtheHealthCareWorkforce.pdf>.

410 *How PACE Works*, ON LOK LIFEWAYS, <https://onloklifeways.org/how-pace-works> (last visited Aug. 15, 2016).

411 *Who We Serve: The On Lok Lifeways PACE Program Is the Perfect Alternative to a Nursing Home*, ON LOK LIFEWAYS, <https://onloklifeways.org/who-we-serve/#learnmore> (last visited Aug. 15, 2016).

412 *Frequently Asked Questions (FAQ)*, ON LOK LIFEWAYS, <https://onloklifeways.org/faqs> (last visited Aug. 15, 2016). The programs receive a capitated rate from Medicare and Medicaid that in 2008 was \$4900 per member, per month. See INST. OF MED., *supra* note 409, at 105.

funds available for investment in the programs' growth. On Lok program evaluations show high participant satisfaction, improved health and physical functioning, improved quality of life, and lower mortality.⁴¹³ At the same time, they free up informal caregivers for all or part of the work week.

A newer private-sector experiment is the Green House movement. Started by a doctor who wanted a better way to care for frail elderly than in nursing homes and with seed funding by the Robert Wood Johnson Foundation, Green House intends to be a "homelike" community-based care setting.⁴¹⁴ People live in a private room with a bathroom in a small, technology-equipped home for eight to ten residents. They eat communally. Green House accepts both Medicaid and Medicare reimbursement. As of the end of 2014, 167 Green Houses had over 1700 people living in them, and 108 new homes were in development.⁴¹⁵ They have had particular success recruiting and retaining caregivers, whom they call "shahbazim" and pay ten percent more than certified nursing assistants. Green House can afford higher salaries because of extremely low turnover and the shahbazims' responsibility for a broad range of activities, from personal care to cooking to housekeeping.⁴¹⁶

Early research on Green House also indicates positive outcomes.⁴¹⁷ Anecdotal evidence in a recent *New York Times* article describes one older woman who "needed help eating and rarely spoke" but within a day of moving into a Green House, fed herself and sang *Amazing Grace*.⁴¹⁸ Even if not all residents are so dramatically altered, this program creates smaller-scale, community-based care options for families who are reticent to "put mom in a nursing home."

An obvious challenge is scaling such models in a way that they retain their quality and remain affordable for more than just the wealthiest families. One intriguing aspect of Green Houses is that community members have donated land and professional services to build facilities, lowering fixed costs.⁴¹⁹ For lower-income residents, On Lok received Department of Housing and Urban Development funds for its residential facilities. The ability to combine public and private funds in both programs creates growth opportunity and access for more people. Yet, even with many of these elements in place,

⁴¹³ INST. OF MED., *supra* note 409, at 85.

⁴¹⁴ *Id.* at 81-82.

⁴¹⁵ Jane E. Brody, *The Green House Effect: Homes for the Elderly to Thrive*, N.Y. TIMES (Dec. 15, 2014, 10:21 AM), <http://well.blogs.nytimes.com/2014/12/15/moving-away-from-nursing-homes>.

⁴¹⁶ See INST. OF MED., *supra* note 409, at 82-83.

⁴¹⁷ *Id.*

⁴¹⁸ Brody, *supra* note 415.

⁴¹⁹ *Id.*

programs have not scaled well.⁴²⁰ If we understand these kinds of programs as necessary to mitigating next-friend risk, learning how to scale them should be higher priority.

One of the greatest infrastructure challenges is the caregiver labor shortage. By one estimate, 3.5 million additional health providers, including nearly 1.6 million registered nurses and nursing aides, will be needed by 2030 just to maintain already insufficient provider-to-population ratios.⁴²¹ Meeting the needs of the elderly will be especially hard because of a gap in geriatric care training.⁴²²

Higher wages are needed to spur labor growth.⁴²³ That said, higher wages on their own might be insufficient. As one scholar bluntly recognizes: “Helping people to dress, eat, urinate, and defecate simply is not an attractive career. Dealing with individuals in various stages of dementia is trying.”⁴²⁴ He adds that the lack of respect, little room for advancement, and stress of these jobs is not easily defrayed with money.⁴²⁵ Efforts to overcome the aspects that could be improved are thus even more critical; without high-quality options, many people will be unwilling to outsource care.

4. *Reshaping the Social and Institutional Baseline*

Finally, addressing the many ways that existing legal and social norms and institutions bias care choices is beyond the scope of this article but nonetheless important for policy development. As one example, FMLA job-leave protections may be insufficient to support efforts to balance caregiving and paid work.⁴²⁶

FMLA leave is limited to caregiving for a spouse, child, or parent, leaving out the many people who care for grandparents, siblings, aunts and uncles, or close friends.⁴²⁷ Furthermore, some of its terms have been interpreted to exclude activities common in long-term caregiving.⁴²⁸ For example, the term “provide care” has been interpreted to exclude time spent moving a parent into a new living arrangement that better met her health

420 See INST. OF MED., *supra* note 409, at 105.

421 *Id.* at 124-25.

422 *Id.* at 128-36.

423 Even with the labor shortage of care professionals, wages have remained stagnant or declined slightly over the past decade. *America’s Direct-Care Workforce*, *supra* note 297, at 4-5 (2013).

424 White, *supra* note 226, at 63.

425 *Id.*

426 See generally Smith, *Elder Care*, *supra* note 126, at 382 (describing some of the shortfalls of FMLA coverage in cases of elder care).

427 29 U.S.C. § 2612(a)(1)(C) (2012).

428 See Smith, *Elder Care*, *supra* note 126, at 393.

needs.⁴²⁹ The complexity of FMLA makes it difficult for people to understand what is covered.⁴³⁰ Finally, twelve weeks of leave may be too short in many cases, considering that the average period of informal care lasts 4.6 years.⁴³¹ It is unrealistic to expect employers to hold jobs open for years, and this expectation would also be unproductive since such mandates can shift costs to workers. However, something more than twelve weeks is needed in some situations.⁴³² The point is that there are many ways we could address these broader legal or social factors that exacerbate next-friend risk.

CONCLUSION

Taking next-friend risk seriously fundamentally shifts what it means to solve the long-term care crisis. It is not just a crisis faced by people who suffer from prolonged illness or disability. It is equally a crisis for their children, parents, siblings, grandchildren, aunts and uncles, and closest friends, who sacrifice their own wellbeing to care for them. They are interrupting their careers, their relationships, and their life pursuits. These next friends are invisibly bearing the costs of caring and experiencing disquieting insecurity in their own lives.

By seeing these costs as evidence of an insurable risk and pursuing policies that are more sensitive to this risk, we can create a society in which some people, especially women, no longer experience severe harms due to the tragic misfortune of having a loved one become ill or disabled. Better long-term care policy, defined as policy that aims equally to mitigate next-friend risk, can solve a problem that is perpetuating deep social inequities and can provide greater security for all families.

Reimagining risk is an exercise with import beyond long-term care. Most social insurance programs and many regulations are based on implicit definitions of the risks that are worthiest of collective attention. By illustrating one field in which a narrow definition of risk has created an unstable foundation for policy-making, this article invites further examination of the law's role in inscribing obligation for some and security for others by how it imagines risk.

429 *Pang v. Beverly Hosp., Inc.*, 94 Cal. Rptr. 2d 643, 649-51 (Ct. App. 2000).

430 See Nancy R. Daspit, *The Family and Medical Leave Act of 1993: A Great Idea but a "Rube Goldberg" Solution?*, 43 EMORY L.J. 1351, 1352 (1994).

431 NAT'L ALLIANCE, CAREGIVING, *supra* note 80, at 19. This average is skewed by certain relationships, such as parents caring for children with disabilities (9.5 years on average). *Id.* at 20.

432 ALSTOTT, NO EXIT, *supra* note 22, at 154-62. But evidence suggests the FMLA has not resulted in such cost shifting so far. *Id.* at 159.

Rehabilitation, Education, and the Integration of Individuals with Severe Brain Injury into Civil Society: Towards an Expanded Rights Agenda in Response to New Insights from Translational Neuroethics and Neuroscience

Megan S. Wright and Joseph J. Fins*

Abstract: Many minimally conscious patients are segregated in nursing homes, and are without access to rehabilitative technologies that could help them reintegrate into their communities. In this Article, we argue that persons in a minimally conscious state or who have the potential to progress to such a state must be provided rehabilitative services instead of being isolated in custodial care. The right to rehabilitative technologies for the injured brain stems by analogy to the expectation of free public education for children and adolescents, and also by statute under the Americans with Disabilities Act and under Supreme Court jurisprudence, namely the leading deinstitutionalization case, *Olmstead v. L.C.* ex rel. *Zimring*.

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TABLE OF CONTENTS

TABLE OF CONTENTS.....	234
INTRODUCTION.....	236
I. THE PROBLEM OF LACK OF ACCESS TO REHABILITATION FOR MINIMALLY CONSCIOUS PATIENTS	240
A. MINIMALLY CONSCIOUS STATE DEFINED	240
1. COMA	241
2. VEGETATIVE STATE.....	241
3. MINIMALLY CONSCIOUS STATE	242
B. IMPORTANCE OF REHABILITATION FOR PERSONS IN A MINIMALLY CONSCIOUS STATE.....	243
C. PERSONS IN A MINIMALLY CONSCIOUS STATE OFTEN LACK ACCESS TO REHABILITATION	245
D. CONSEQUENCES OF LACK OF ACCESS TO REHABILITATION FOR PERSONS IN A MINIMALLY CONSCIOUS STATE	247
E. HOW THE INJURED BRAIN IS SIMILAR TO THE DEVELOPING BRAIN.....	249
II. IMPERATIVE TO PROVIDE REHABILITATION TO THE INJURED BRAIN ...	251
A. BY ANALOGY TO EXPECTATION OF ACCESS TO FREE PUBLIC EDUCATION	251
1. EXPECTATION OF ACCESS TO FREE PUBLIC EDUCATION	251
2. REHABILITATION OF AN INJURED BRAIN IS SIMILAR TO EDUCATION OF A DEVELOPING BRAIN	256
3. IF UNDERSTOOD AS EDUCATION, MINIMALLY ADEQUATE REHABILITATION OF INJURED BRAIN IS ETHICALLY COMPELLED.....	257
B. BY STATUTE AND CASE LAW.....	259
1. PURPOSE OF THE REHABILITATION ACT OF 1973, ADA, ADAAA, AND <i>OLMSTEAD</i>	259
2. HOW LACK OF ACCESS TO REHABILITATION FOR THOSE IN MCS VIOLATES THE ADA AND <i>OLMSTEAD</i>	267
3. LEGAL REMEDIES AVAILABLE TO PERSONS WITH DOCs UNDER THE ADA.....	272
4. COUNTERARGUMENTS AND REBUTTALS	275

III. REFORMS TO REALIZE THE RIGHT TO REHABILITATION.....	277
A. PROPOSED CHANGES TO MEDICARE POLICIES	277
B. CAPABILITIES APPROACH	279
C. COUNTERARGUMENTS AND REBUTTALS	281
CONCLUSION	285

INTRODUCTION

“[N]ew insights and societal understandings can reveal unjustified inequality within fundamental institutions that once passed unnoticed and unchallenged”¹

As neuroscience evolves, the law is called upon to respond. In this Article, we focus on the rights of people with severe brain injury and subsequent disorders of consciousness. In particular, we focus on the right to rehabilitative technologies to aid in communication, which will aid in community integration. The arguments we put forth in this Article are responsive to advances in translational neuroscience.

This Article examines how changing medical practice and developments in neuroscience create new classes of persons with disabilities. Given the lack of categories and conceptualizations of the existence and needs of such persons, the law needs to respond and address their civil rights. We aim to apply neuroscience to law in a way that expands civil liberties.²

In the last decades of the 20th century, medicine has evolved to save the lives of patients with traumatic brain injuries who otherwise would have died or ended up in a permanent vegetative state as a result of their injuries. When a person has a traumatic brain injury, the brain swells. Because the skull does not provide room for the swelling, the brain herniates downward, potentially resulting in death or a persistent vegetative state.³ New techniques have advanced to manage elevated intracranial pressure, however, and now part of the skull can be removed (i.e., craniotomy and craniectomy).⁴ These medical advances saved lives, but injured persons are often profoundly disabled. Some are left with a disorder of consciousness, such as the vegetative state or minimally conscious state.⁵ The vegetative state is well known through landmark court cases, but the minimally conscious state less so.

1 *Obergefell v. Hodges*, 135 S. Ct. 2584, 2603 (2015).

2 In contrast, the neuroscience, neuroethics, and law agenda is dominated by scholars and funders who focus on what some call “criminal neuroscience.” See, e.g., *MacArthur Foundation Research Network on Law and Neuroscience*, VAND. U.L. SCH. (2016), <http://www.lawneuro.org>.

3 M. Ross Bullock et al., *Introduction*, 58 NEUROSURGERY (SUPPLEMENT) S2-1, S2-1 (2006), http://neurosurgery.hr/wp-content/uploads/2012/08/Surgical_Guidelines_article_2.pdf.

4 *Id.*

5 Technology both solved a problem in this case—preventing death—and created a problem—the existence of the minimally conscious state. Technology is now responding to the minimally conscious state, aiming to restore consciousness and communication. For a description of the relationship between technology and neuroethics, see Joseph J. Fins, *Neuroethics and the Lure of Technology*, in *THE OXFORD HANDBOOK OF NEUROETHICS* 895, 904 (Judy Illes & Barbara J. Sahakian eds., 2011) [hereinafter Fins, *Technology*] (“Technology, remember, is a queer thing; it brings you great gifts with one hand, and it stabs you in the back with the other.”).

The minimally conscious state was formally identified as a new diagnostic category in 2002.⁶ Persons in a minimally conscious state have intermittent and inconsistent evidence of consciousness that may or may not manifest behaviorally, and such persons may be mistaken for vegetative.⁷ The advent of this category was made possible by clinical advances discussed later in the Article, and there are resulting ethical, policy, medical, and legal questions.

We are especially concerned in this Article with the legal issues, in particular the lack of appropriate medical and rehabilitative treatment for persons in a minimally conscious state, and how this may violate the Americans with Disabilities Act⁸ and be inconsistent with the putative right to education. Currently, most minimally conscious patients “remain sequestered in nursing homes, incompletely diagnosed . . . at the margins of society,”⁹ without access to rehabilitative technologies that could help integrate them back into their communities.

In this Article, we assert that when there is potential for recovery of consciousness, there is a right to rehabilitative technologies for the injured brain. This right stems by analogy to the expectation of free public education for children and adolescents, and also by statute under the Americans with Disabilities Act¹⁰ and under Supreme Court jurisprudence, namely the leading deinstitutionalization case, *Olmstead v. L.C. ex rel. Zimring*.¹¹ Persons in a minimally conscious state or who have the potential to progress to such a state must be provided rehabilitative services instead of being segregated and isolated in custodial care.

Our argument proceeds as follows. In Part I of this Article, we describe how patients in the minimally conscious state often lack access to rehabilitative

6 See Joseph T. Giacino et al., *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 NEUROLOGY 349 (2002).

7 See Joseph T. Giacino et al., *Disorders of Consciousness After Acquired Brain Injury: The State of the Science*, 10 NATURE REV. NEUROLOGY 99, 100 (2014).

8 The minimally conscious state is currently not a category reflected in the law, unlike the permanent vegetative state, the condition at the forefront of some of the most well-known right-to-die cases, or other medical conditions involving similar levels of cognitive impairment due to degenerative diseases such as Alzheimer’s or due to developmental disorders. Unlike the permanent vegetative state or Alzheimer’s Disease, persons in a minimally conscious state may actually improve, and unlike persons with a developmental disorder, persons in a minimally conscious state previously had capacity and thus had prior wishes. These differences present new questions for law.

9 Joseph J. Fins, *Border Zones of Consciousness: Another Immigration Debate?*, 7 AM. J. BIOETHICS 51, 52 (2007) [hereinafter Fins, *Border Zones*]; see also JOSEPH J. FINS, RIGHTS COME TO MIND: BRAIN INJURY, ETHICS, AND THE STRUGGLE FOR CONSCIOUSNESS (2015) [hereinafter FINS, RIGHTS COME TO MIND] (exploring shortcomings in society’s treatment of individuals in a minimally conscious state).

10 42 U.S.C. §§ 12101-12213 (2012).

11 527 U.S. 581 (1999).

technologies that have been increasingly shown to have the potential to help these patients recover a degree of functional status. In this section, we first define the minimally conscious state, and contrast it with other disorders of consciousness, such as comas and the vegetative state. We then describe investigational and therapeutic drugs and technological innovations that have been shown to have a beneficial effect on some patients with a disorder of consciousness. We next note the reasons why patients do not receive such interventions, and the negative consequences of this lack of access or societal neglect. We conclude this section by previewing our argument that rehabilitating the injured brain can be analogized to educating children whose brains are developing.

In Part II of this Article, we expand upon an argument made in the book *Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness*.¹² We assert that there is a right to rehabilitation for persons with disorders of consciousness. We first argue that given the similar developmental processes that occur in the maturing brain and the recovering brain, the legally created expectation of free public education, which is so important to fulfilling the potential of the maturing brain, should be extended to individuals with severe brain injury where a regenerative process recapitulates an earlier developmental script.¹³ Given the homology of developmental biology and brain repair, and the utility and ubiquity of education in early life, we argue that restorative efforts directed at the injured brain are better understood as an educational process than solely as a rehabilitative act.¹⁴ Expanding our conception of rehabilitation to include education places these efforts beyond a mere medical care entitlement and into the sphere of legally created expectations, which are both grounded in statute such as the Individuals with Disabilities Education Act (IDEA)¹⁵ and also No Child Left Behind,¹⁶ constitutional analysis, and common sense.

We then argue that based on the Americans with Disabilities Act (ADA), including subsequent amendments to and case law interpreting the Act, there is a statutory right to rehabilitation for brain-injured persons with disorders of consciousness receiving treatment from healthcare facilities and residing in custodial care facilities. Currently, without such access to rehabilitative technologies, conscious or potentially conscious persons are segregated and isolated in custodial care facilities, and are not receiving necessary treatment, which violates the purpose of the ADA.¹⁷ Furthermore, persons with disorders of

12 FINS, RIGHTS COME TO MIND, *supra* note 9.

13 *Id.* at 306-07.

14 *Id.*

15 Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400-82 (2012).

16 No Child Left Behind (NCLB) Act of 2001, 20 U.S.C. § 6301 (2012).

17 FINS, RIGHTS COME TO MIND, *supra* note 9, at 289-92.

consciousness are not given access to auxiliary aids (such as drugs, devices, neuroimaging, neuroprosthetics, and rehabilitation) that would assist them in communicating with their healthcare providers and caregivers, which violates the statutory and regulatory requirements of the ADA. Finally, given that the ADA was amended to expand rights to the disabled, and was modeled after and is a legacy of civil rights legislation, we should expect that courts will increase protections and rights for this newly recognized class of disabled persons with their unique communication needs. We do not argue for further amendments to the ADAAA, but rather the application of this legislation to persons with disorders of consciousness, and we describe how remedies under the ADA are potentially available to persons with disorders of consciousness who lack access to rehabilitative technologies.

In Part III of this Article, we explore some necessary changes to implement the content of a right to rehabilitation beyond providing rehabilitative technologies for those with disorders of consciousness. We suggest some policy changes, such as changing Medicare payment criteria, which would make more persons with disorders of consciousness eligible for specialized rehabilitative care. It is important to note, however, that entitlement reform is a necessary but not sufficient component of reform.¹⁸ Such reform does not address the fundamental marginalization of persons with disorders of consciousness, who are disregarded by society and the law. The application of a statutory right to reasonable accommodations, which for this population is access to rehabilitative technologies, is likewise insufficient. Persons with disorders of consciousness need both a right to rehabilitation, which symbolically asserts that their integration into the community is important, as well as entitlement reform that provides one avenue for them to access such rehabilitation.

Thus, we explore the capabilities approach espoused by social scientists and philosophers such as Amartya Sen,¹⁹ Martha Nussbaum,²⁰ and Sridhar Venkatapuram.²¹ We suggest here and elsewhere²² how this school of thought

18 *Id.* at 287 (“And even now, I have no doubt that harmonizing time frames of recovery and reimbursement streams would advance care, decrease capricious denials, and lead to rehabilitation trials of appropriate duration. But . . . I am not convinced that reimbursement reform will happen without fundamentally changing how we view the minimally conscious, their needs, and their place in society.”).

19 *See generally* AMARTYA SEN, *COMMODITIES AND CAPABILITIES* (1999) (relating ability to function to overall wellbeing).

20 *See generally* MARTHA NUSSBAUM, *CREATING CAPABILITIES: THE HUMAN DEVELOPMENT APPROACH* (2013) (arguing for measures of progress that account for the basic human needs for dignity and self-respect).

21 *See generally* SRIDHAR VENKATAPURAM, *HEALTH JUSTICE* (2011) (applying the “capabilities approach” to health and health care, asserting that there exists a moral right to be healthy).

22 FINS, *RIGHTS COME TO MIND*, *supra* note 9, at 293-94; Joseph J. Fins et al., *Whither the*

bridges the right to rehabilitation with the technologies that can enable this process leading to the furtherance of the civic integration of persons with disorders of consciousness, which is what truly enhances freedom, dignity, and community for persons with brain injury and disorders of consciousness.

Finally, we acknowledge that there is a cost to implementing this right to rehabilitative technologies, but assert that the ADA limits the effect that cost considerations can have in denying access to accommodations and modifications, and also point to other considerations in a cost-benefit analysis that may be useful. We also address concerns that this issue is not yet ripe given the experimental nature of some of the rehabilitative technologies we describe. Our arguments should be understood as relevant to the current state of medical technologies, but also as anticipating future scientific advances; our legal theories are anticipating changes in medical practice.

We conclude by noting that if a right to rehabilitation of the injured brain is recognized, such recognition would also be in line with recent Supreme Court jurisprudence articulating ideals of dignity for all.²³

I. THE PROBLEM OF LACK OF ACCESS TO REHABILITATION FOR MINIMALLY CONSCIOUS PATIENTS

A. Minimally Conscious State Defined

Disorders of consciousness (DOCs) include coma, vegetative state, and the minimally conscious state.²⁴ The legal community is likely most familiar with what has been called the vegetative state, the medical condition at the heart of high-profile cases such as *Quinlan*,²⁵ *Cruzan*,²⁶ and *Schiavo*.²⁷ This Section will briefly define each of these DOCs to orient the reader to the subject matter of this

"Improvement Standard"? Coverage for Severe Brain Injury After *Jimmo v. Sebelius*, 44 J.L. MED. & ETHICS 182 (2016).

23 See, e.g., *Obergefell v. Hodges*, 135 S. Ct. 2584, 2589 ("The fundamental liberties protected by the Fourteenth Amendment's Due Process Clause extend to certain personal choices central to individual dignity and autonomy . . .").

24 Some readers may wonder whether the locked-in syndrome is also a disorder of consciousness. The locked-in syndrome differs from disorders of consciousness in that a person in such a state is awake and conscious but unable to move (i.e., paralyzed) or speak. Giacino et al., *supra* note 7, at 101 (describing how the locked-in syndrome compares with disorders of consciousness); Steven Laureys et al., *The Locked-In Syndrome: What Is It Like To Be Conscious but Paralyzed and Voiceless?*, 150 PROGRESS BRAIN RES. 495 (2005) (describing the locked-in syndrome).

25 *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

26 *Cruzan ex rel. Cruzan v. Mo. Dep't of Health*, 497 U.S. 261 (1990).

27 The last in a long line of cases is *Schiavo ex rel. Schlinder v. Schiavo*, 403 F.3d 1294 (11th Cir. 2005).

paper and update diagnostic classifications, which have refined the vegetative state category into distinct subcategories based on whether it is persistent or permanent. We will also introduce a new category, the minimally conscious state, which is often confused with the vegetative state.

1. Coma

“The defining clinical feature of coma is the complete loss of spontaneous or stimulus-induced arousal.”²⁸ A coma typically lasts a few weeks after a brain injury.²⁹ “After receiving an injury severe enough to cause a coma, a self-limited and eye-closed state of unresponsiveness, a patient may: recover; sustain whole brain death; or pass into the vegetative state.”³⁰

2. Vegetative State³¹

A vegetative state (VS) is one in which a person is unconscious, but seemingly “wakeful.”³² This means that a patient’s eyes may be open, but she lacks all other markers of consciousness, such as the ability to communicate or understand commands. Additionally, any movement she makes is purposeless, a result only of a functioning brain stem.³³ Jennett and Plum describe this state as wakeful unresponsiveness.³⁴ Such persons are “unaware of self or environment.”³⁵ If a patient is in a VS for more than thirty days, she is said to be in a persistent vegetative state.³⁶ If the VS is a result of anoxic brain injury³⁷ and

28 Giacino et al., *supra* note 7, at 100.

29 Joseph J. Fins, *Being Conscious of Their Burden: Severe Brain Injury and the Two Cultures Challenge*, 1157 ANN. N.Y. ACAD. SCI. 131, 135 (2009) [hereinafter Fins, *Conscious Burden*].

30 Joseph J. Fins, *Minds Apart: Severe Brain Injury, Citizenship, and Civil Rights*, in 13 LAW AND NEUROSCIENCE: CURRENT LEGAL ISSUES 367, 372 (Michael Freeman ed., 2010) [hereinafter Fins, *Minds Apart*].

31. The seminal paper on the vegetative state is Bryan Jennett & Fred Plum, *Persistent Vegetative State After Brain Damage: A Syndrome in Search of a Name*, 299 LANCET 734 (1972).

32 Fins, *Conscious Burden*, *supra* note 29, at 137; see Joseph J. Fins, *Lessons from the Injured Brain: A Bioethicist in the Vineyards of Neuroscience*, 18 CAMBRIDGE Q. HEALTHCARE ETHICS 7, 7 (2009) [hereinafter Fins, *Lessons*]; Joseph J. Fins, *Neuroethics, Neuroimaging, and Disorders of Consciousness: Promise or Peril*, 122 TRANSACTIONS AM. CLINICAL & CLIMATOLOGICAL ASS’N 336, 338 (2010) [hereinafter Fins, *Neuroethics*]; Giacino et al., *supra* note 7, at 100.

33 Joseph J. Fins, *Affirming the Right to Care, Preserving the Right to Die: Disorders of Consciousness and Neuroethics After Schiavo*, 4 PALLIATIVE & SUPPORTIVE CARE 169, 172 (2006) [hereinafter Fins, *Right to Care*]; Fins, *Lessons*, *supra* note 32, at 7; Fins, *Minds Apart*, *supra* note 30, at 368-69; Fins, *Neuroethics*, *supra* note 32, at 338; Giacino et al., *supra* note 7, at 100.

34 Jennett & Plum, *supra* note 31, at 734.

35 Multi-Soc’y Task Force on PVS, *Medical Aspects of the Persistent Vegetative State, Part I*, 330 NEW ENG. J. MED. 1499, 1500 (1994) [hereinafter Task Force]; see Fins, *Conscious Burden*, *supra* note 29, at 137; Fins, *Lessons*, *supra* note 32, at 7; Fins, *Neuroethics*, *supra* note 32, at 338.

36 Task Force, *supra* note 35, at 1501; see Fins, *Minds Apart*, *supra* note 30, at 372; Fins,

persists for more than three months, the patient is reclassified as being in a permanent vegetative state.³⁸ If the VS is a result of traumatic brain injury and persists for more than twelve months, the patient is likewise reclassified as being in a permanent vegetative state.³⁹ If properly diagnosed, there is no hope for recovery once a patient is classified as being in a permanent vegetative state.⁴⁰

3. Minimally Conscious State

A consensus statement on the minimally conscious state (MCS) was not articulated until relatively recently. The MCS became a formal diagnostic category in 2002.⁴¹ As the science of medical care for the injured brain advanced, it became possible for patients who previously might have died or ended up in a permanent vegetative state to recover consciousness to some degree.⁴² These advances included surgical interventions such as the use of intraventricular shunts and craniotomy used to treat closed head injuries, mitigating or preventing herniation or death.⁴³ With such interventions, patients can now have a different trajectory.

The MCS is distinct from a VS in that it “is a condition of severely altered consciousness characterized by minimal but definite behavioral evidence of self or environmental awareness.”⁴⁴ “Patients in the MCS have definitive evidence of consciousness, demonstrating intention, attention, memory, and awareness of the self, others, or the environment.”⁴⁵ A person can progress from a coma or not yet

Right to Care, *supra* note 33, at 173.

37 This occurs when the brain has been deprived of oxygen.

38 Fins, *Right to Care*, *supra* note 33, at 173; Fins, *Conscious Burden*, *supra* note 29, at 137; Fins, *Border Zones*, *supra* note 9, at 52; Fins, *Minds Apart*, *supra* note 30, at 372; Fins, *Neuroethics*, *supra* note 32, at 339; Giacino et al., *supra* note 7, at 100.

39 Fins, *Right To Care*, *supra* note 33, at 173; Fins, *Conscious Burden*, *supra* note 29, at 137; Fins, *Border Zones*, *supra* note 9, at 52; Fins, *Minds Apart*, *supra* note 30, at 372; Fins, *Neuroethics*, *supra* note 32, at 339; Giacino et al., *supra* note 7, at 100.

40 Fins, *Minds Apart*, *supra* note 30, at 372; Fins, *Neuroethics*, *supra* note 32, at 340. The condition is distinct from brain death, however, in that the brain stem is still intact and regulating bodily functions such as breathing. Fins, *Lessons*, *supra* note 32, at 7-8; Fins, *Neuroethics*, *supra* note 32, at 338. In brain death, “no brainstem functions are preserved and these patients do not exhibit spontaneous respiration when challenged with an apnea examination.” Fins, *Neuroethics*, *supra* note 32, at 337.

41 Giacino et al., *supra* note 6. Giacino first labeled this category the MCS in 1997, but the term was not accepted until 2002. Fins, *Lessons*, *supra* note 32, at 9; *see also* FINS, RIGHTS COME TO MIND, *supra* note 9, at 71-79 (describing Giacino’s involvement in developing the category of the MCS).

42 Bullock et al., *supra* note 3, at S2-1.

43 *Id.*

44 Giacino et al., *supra* note 7, at 100.

45 Fins, *Neuroethics*, *supra* note 32, at 340.

permanent VS to a MCS.⁴⁶ There is no definitive information about how many persons exist in a MCS.⁴⁷

The MCS is often difficult to diagnose because of “response inconsistency” in which at one point there may be evidence of “volitional behavior” but not at another.⁴⁸ Furthermore, some minimally conscious persons may not have any motor function, which makes diagnosis without neuroimaging difficult.⁴⁹ Improperly diagnosing the MCS as permanent VS, however, may mean termination of life support, improper medical care such as not providing pain medication,⁵⁰ not providing rehabilitation, and depriving such persons of community.⁵¹

Recovery of functions for persons in the MCS may take years or decades.⁵² Even with recovery, persons who had a DOC from a severe brain injury may be disabled for the remainder of their lives.⁵³

B. Importance of Rehabilitation for Persons in a Minimally Conscious State

Rehabilitation-oriented treatments for those with a DOC are meant to aid them in recovering “consciousness, communication, and functional competency.”⁵⁴ Some studies have shown that almost seventy percent of patients with traumatic brain injury who receive inpatient rehabilitation recover consciousness, and just over twenty percent are able to be functionally independent again.⁵⁵

⁴⁶ *Id.*; Giacino et al., *supra* note 7, at 100.

⁴⁷ See FINS, RIGHTS COME TO MIND, *supra* note 9, at 287; Joseph J. Fins et al., *Late Recovery from the Minimally Conscious State: Ethical and Policy Implications*, 68 *NEUROLOGY* 304, 306 (2007) [hereinafter Fins et al., *Late Recovery*]; Joseph J. Fins et al., *The Minimally Conscious State: A Diagnosis in Search of an Epidemiology*, 64 *JAMA NEUROLOGY* 1400 (2007) (calling for epidemiological studies on the MCS);

⁴⁸ Fins, *Neuroethics*, *supra* note 32, at 340 (“The challenge is that these behaviors are episodic and intermittent and not reproducible, making these patients indistinguishable from vegetative patients to the untrained eye, especially in an isolated single examination.”); Giacino et al., *supra* note 7, at 100, 103.

⁴⁹ FINS, RIGHTS COME TO MIND, *supra* note 9, at 300.

⁵⁰ Patients in a MCS have intact pain networks. Steven Laureys et al., *Cortical Processing of Noxious Somatosensory Stimuli in the Persistent Vegetative State*, 17 *NEUROIMAGE* 732 (2002).

⁵¹ Giacino et al., *supra* note 7, at 103.

⁵² Fins, *Conscious Burden*, *supra* note 29, at 137-38.

⁵³ FINS, RIGHTS COME TO MIND, *supra* note 9, at 113 (describing the variance in recovery from severe brain injury).

⁵⁴ Giacino et al., *supra* note 7, at 107.

⁵⁵ Risa Nakase-Richardson et al., *Longitudinal Outcome of Patients with Disordered Consciousness in the NIDRR TBI Model Systems Program*, 29 *J. NEUROTRAUMA* 59 (2012); see also FINS, RIGHTS COME TO MIND, *supra* note 9, at 288-89 (describing the Nakase-Richardson et al. study). These numbers are likely conservative estimates of the potential effect of rehabilitation on those with severe brain injury and subsequent DOCs.

One intervention that has been shown to be effective for patients in a VS or MCS is amantadine, a drug used to treat influenza. One large, randomized controlled study showed that amantadine could accelerate recovery from a VS.⁵⁶ Zolpidem, a sleep aid, is another pharmacological intervention that has also been demonstrated to be effective for a small minority of patients with a DOC.⁵⁷

There is also some evidence of effectiveness of non-pharmacological interventions. Neuroprosthetics may be used to aid in communication and recovery.⁵⁸ Neuroprosthetics include communication boards or other similar devices, deep brain stimulation (DBS), and neuroimaging.⁵⁹ Neuroimaging is functional magnetic resonance imaging (fMRI) scans and positron emission tomography (PET).⁶⁰ To assess whether a behaviorally nonresponsive patient is conscious or to communicate with a conscious patient who has no or limited motor function, scans are made of the patient while they are asked to think about performing different tasks to indicate either “yes” or “no” in response to questions.⁶¹ Also, a pilot study (or proof of principle study) of DBS of the central thalamus demonstrated behavioral improvements for one patient with a DOC.⁶²

56 Joseph T. Giacino et al., *Placebo-Controlled Trial of Amantadine for Severe Traumatic Brain Injury*, 366 NEW ENG. J. MED. 819 (2012) (demonstrating that recovery is accelerated for patients with DOC who are given amantadine relative to a placebo over a four-week period while receiving inpatient rehabilitation, and suggesting that future research focus on whether long-term outcomes are improved).

57 John Whyte & Robin Myers, *Incidence of Clinically Significant Responses to Zolpidem Among Patients with Disorders of Consciousness: A Preliminary Placebo Controlled Trial*, 88 AM. J. PHYSICAL MED. & REHAB. 410 (2009) (showing that one patient in the VS shifted to the MCS after receiving zolpidem, but this drug had no effect on the other 14 participants in the study).

58 Some have noted the high cost of neuroimaging and have argued that access to lower cost alternatives such as pharmacological agents to restore consciousness and communication may be more practical. See, e.g., FINS, RIGHTS COME TO MIND, *supra* note 9, at 301. Some organizations are creating low-cost, individually tailored devices that can aid those with brain injury to communicate. See, e.g., SPEAK YOUR MIND FOUNDATION, <http://speakyourmindfoundation.org> (last visited Oct. 10, 2015).

59 The founder of Speak Your Mind Foundation describes a customized, low-cost communication device, which consisted of a set of glasses, camera, and software that helped a young woman who had a brain stem stroke communicate. *Id.* The total cost of the device is \$30, and it enabled communication that would otherwise be impossible. *Id.* Similar devices on the market cost \$15,000. *Id.*

60 See Fins, *Neuroethics*, *supra* note 32, at 336.

61 See Fins, *Minds Apart*, *supra* note 30, at 376 (noting the “disturbing possibility of consciousness obscured by a physical incapacity to communicate and make one’s presence known”); see also Joseph J. Fins & Nicholas D. Schiff, *In the Blink of the Mind’s Eye*, 40 HASTINGS CTR. REP. 21, 21 (2010) (reporting how an fMRI could allow patients to communicate preferences while in a MCS).

62 See Nicholas D. Schiff et al., *Behavioural Improvements with Thalamic Stimulation After Severe Traumatic Brain Injury*, 488 NATURE 600, 601 (2007) (reporting on a study of one patient who regained some language capacity and the ability to swallow food).

Additionally, physical therapy may also be effective.⁶³

Most of these interventions are investigational,⁶⁴ but this does not mean that they should not be made available to patients in DOC through access to clinical trials.⁶⁵ Scientific research has demonstrated that drugs and devices can functionally augment consciousness and communication for these patients;⁶⁶ further translational research may lead to more progress and discovery.⁶⁷

While there may be spontaneous recovery from a coma or VS to a MCS, it is important that those with a DOC receive available rehabilitation-oriented treatments. Rehabilitation will aid in accurately assessing a patient's diagnostic state, which will then aid with prognosis. Using rehabilitative techniques may prevent premature withdrawal of life support from those who are conscious or have the potential to be conscious.⁶⁸ Additionally, rehabilitation may lead patients to be able to convey whether they are experiencing pain, which will then lead to better medical treatment.⁶⁹ Perhaps most importantly, rehabilitation may make it possible for patients with a DOC to communicate with their family members.

C. Persons in a Minimally Conscious State Often Lack Access to Rehabilitation

Patients who have a DOC often lack access to rehabilitation that could aid them in recovering consciousness and functional abilities. There are several reasons for this lack of access. One reason is the high rate of misdiagnosis of the

63 Linda E. Mackay et al., *Early Intervention in Severe Brain Injury: Long-Term Benefits of a Formalized Program*, 73 ARCHIVES PHYSICAL MED. & REHAB. 635 (1992).

64 Some are not experimental per se, but rather are off-label uses of prescription drugs.

65 FINS, RIGHTS COME TO MIND, *supra* note 9, at 295.

66 See, e.g., Giacino et al., *supra* note 7 (summarizing the state of scientific research).

67 *Id.* But see Joseph J. Fins & Barbara Pohl, *Guardianship and the Injured Brain: Representation and the Rights of Patients and Families*, in FINDING CONSCIOUSNESS (Sinnott-Armstrong, ed.) (2016) (discussing how guardianship may be problematic for persons with DOC); Megan S. Wright et al., *Guardianship and Clinical Research Participation: The Case of Wards with Disorders of Consciousness*, 27 KENNEDY INST. ETHICS J. (forthcoming 2016) (discussing how guardianship for this population may impede access to research or experimental interventions that may aid those with DOCs, and recommending that state guardianship laws permit guardians to consent on behalf of their wards to such research or interventions).

68 Professor Fins has repeatedly written about patients who are presumed “hopeless” but in fact are conscious or have the capacity to regain consciousness. See, e.g., FINS, RIGHTS COME TO MIND, *supra* note 9, at 98 (describing the erroneous presumption that a patient was “hopeless” and vegetative when in fact she was in a MCS); Fins, *Right to Care*, *supra* note 33, at 174 (noting that mistaken assumptions about patients in a MCS can “erroneously support decisions to prematurely withhold and/or withdraw life-sustaining therapy before the patient has had time to declare him or herself prognostically”); see also Fins et al., *Late Recovery*, *supra* note 47, at 306 (arguing that decisions about life-sustaining for patients with DOC be fully and scientifically informed).

69 *Id.* at 301 (describing how patients in MCS may be in pain, but unable to communicate it); Giacino et al., *supra* note 7, at 9 (describing how those in MCS should have pain treated because they can subjectively experience pain unlike those in VS).

MCS. Some studies cite a misdiagnosis rate of approximately 30-40%.⁷⁰ The rate of misdiagnosis is high, in part, because of the intermittent consciousness a patient in MCS experiences,⁷¹ and because without proper neuropsychiatric testing, it may be impossible to recognize or elicit behavioral manifestations of consciousness.⁷² It is also due to the recentness of the diagnostic category and lack of knowledge in the broader medical community about this condition.⁷³ It is also because

patients with disorders of consciousness may need a longer period of time to declare themselves than other critically ill patients in the acute care setting. In a setting where decisional constructs operate in days and weeks, and not months, it becomes too easy to mistake the failure to improve quickly as an indication that no improvement will be possible at all.⁷⁴

If patients are incorrectly assessed as being in a permanent VS rather than MCS, they will not receive rehabilitation because those in a permanent VS by definition cannot recover.⁷⁵

Another reason that patients with DOC lack access to rehabilitation is what has been referred to as the “culture of nihilism” surrounding severe brain injury.⁷⁶ Given that patients with severe brain injury and subsequent DOC may be viewed as hopeless by health care professionals and society at large, perhaps in part due

⁷⁰ Caroline Schnakers et al., *Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus Versus Standardized Neurobehavioral Assessment*, 9 BMC NEUROLOGY 35 (2009).

⁷¹ Fins, *Neuroethics*, *supra* note 32, at 340-41 (“The behaviors that patients manifest in consciousness are episodic and intermittent but definite. They are not captured in a single examination, and if a family sees a behavior and only reports it to a nursing home staff, the staff are likely to discount the observation, chalking it up to denial, especially when the patient has come from an academic medical center in which the patient was definitely diagnosed as being vegetative.”).

⁷² Some patients may not have motor function. *See* FINS, RIGHTS COME TO MIND, *supra* note 9, at 300; Fins, *Neuroethics*, *supra* note 32, at 343 (summarizing a study wherein patients who were thought to be vegetative were shown to be minimally conscious after being able to use yes/no communication through neuroimaging); Joseph T. Giacino et al., *The JFK Coma Recovery Scale-Revised: Measurement Characteristics and Diagnostic Utility*, 85 ARCHIVES PHYSICAL MED. & REHAB. 2020 (2004) (describing how the revised coma recovery scale was able to identify persons as being in a minimally conscious state who were formally diagnosed as being in a persistent vegetative state).

⁷³ Fins, *Conscious Burden*, *supra* note 29, at 137 (referring to a “knowledge deficit” of physicians about the MCS).

⁷⁴ Fins, *Right to Care*, *supra* note 33, at 173-74.

⁷⁵ Fins, *Neuroethics*, *supra* note 32, at 340.

⁷⁶ FINS, RIGHTS COME TO MIND, *supra* note 9, at 82; Fins, *Conscious Burden*, *supra* note 29, at 134-36; Fins, *Lessons*, *supra* note 32, at 7.

to highly publicized right-to-die cases such as *Quinlan*, *Cruzan*, and *Schiavo*, patients in a VS or MCS with potential to recover may not have this potential recognized.⁷⁷ This is especially unfortunate given that as many as half of those with DOC recover to some degree over time.⁷⁸

A final reason that patients with DOC lack access to rehabilitation concerns inpatient rehabilitation admission criteria and health care insurance funding constraints. In the United States, admission to inpatient rehabilitation depends on meeting standards inapplicable to those with DOC. For example, admission or reimbursement standards may require that a patient already be in a MCS upon discharge from a hospital, or may require “medical necessity” or use an “improvement standard.”⁷⁹ Few patients with severe brain injury and subsequent DOC can meet these criteria upon release from the hospital, but if given rehabilitation could recover to the state that is deemed necessary for them to have access to rehabilitation in the first place.⁸⁰

D. Consequences of Lack of Access to Rehabilitation for Persons in a Minimally Conscious State

What happens to patients in a MCS who lack access to rehabilitation that could help them recover? If patients are in a MCS upon discharge from the hospital following medical interventions allowing patients to survive their brain injury, they are sent to inpatient rehabilitation facilities. Patients in a VS,

⁷⁷ See FINS, RIGHTS COME TO MIND, *supra* note 9, at 82; Fins, *Minds Apart*, *supra* note 30, at 368-71; Fins, *Conscious Burden*, *supra* note 29, at 133, 134-36; see also Joseph J. Fins, *Constructing an Ethical Stereotaxy for Severe Brain Injury: Balancing Risks, Benefits, and Access*, 4 NATURE REV. NEUROSCIENCE 323 (2003) (linking the right to die movement and brain injury); Fins, *Minds Apart*, *supra* note 30, at 367 (“Although *Quinlan* was laudable for enfranchising patients and families with a right to die, the case’s legacy has also had the unintended consequence of marginalizing a whole class of patients with disorders of brain injury, presumed to be beyond any hope of recovery and thus undeserving of care.”); Giacino et al., *supra* note 7, at 108-09.

⁷⁸ See Nakase-Richardson et al., *supra* note 55; Giacino et al., *supra* note 7, at 108-109 (describing the ethical implications of the Nakase-Richardson et al. study findings).

⁷⁹ Giacino et al., *supra* note 7, at 109. Many scholars have critiqued medical necessity. See, e.g., FINS, RIGHTS COME TO MIND, *supra* note 9, at 300; Fins, *Conscious Burden*, *supra* note 29, at 132; Fins, *Right to Care*, *supra* note 33, at 174; Fins et al., *supra* note 22. As Professor Fins has noted,

Long before a patient shows signs of improving behaviorally, his brain may demonstrate changes that herald recovery. But medical necessity is a construct that presupposes motor function, a kind of ability that would discriminate against those who cannot move, who cannot respond to a command because they cannot control their limbs. For some minimally conscious patients, the failure to properly assess their minds could lead to the assumption that they were not conscious, when their nonresponse was due to lack of motor function.

FINS, RIGHTS COME TO MIND, *supra* note 9, at 300.

⁸⁰ See Giacino et al., *supra* note 7, at 109.

however, are often discharged from hospitals to nursing homes or other chronic/custodial care facilities.⁸¹ While in nursing homes or other chronic care facilities, they are often not given the rehabilitation that might speed up their potential recovery. Importantly, a patient in a VS could transition into a MCS, but is then lost due to lack of follow up and improper diagnosis. There are two failures in this process: failure to receive rehabilitation, and if there is rehabilitation, it is often too truncated to be as effective as possible.⁸²

The current infrastructure does not allow for patients in a MCS to realize their potential, which may require more precise diagnosis and necessitate specialized treatment. Not all such patients will emerge beyond this state, but their potential for recovery is not realized when they lack access to services that could help them. Furthermore, any signs of their recovery of consciousness, given that their consciousness is intermittent, may be missed given that nursing home staff is not seeking such indications.⁸³ Patients are often surrounded by persons who are elderly⁸⁴ and actively dying, also further conflating their status

81 See FINS, RIGHTS COME TO MIND, *supra* note 9, at 290; Giacino et al., *supra* note 7, at 109. Additionally, families may be encouraged to withhold or withdraw care from the brain-injured person or to donate the patient's organs. Needless to say, if the patient is minimally conscious or has the possibility to become so, such a decision is premature. See FINS, RIGHTS COME TO MIND, *supra* note 9, at 290; Fins, *Right to Care*, *supra* note 33, at 174 (explaining that families may "erroneously support decisions to prematurely withhold and/or withdraw life-sustaining therapy before the patient has had time to declare him or herself prognostically"); Fins, *Conscious Burden*, *supra* note 29, at 134-36.

82 John Whyte & Risa Nakase-Richardson, *Disorders of Consciousness: Outcomes, Comorbidities, and Care Needs*, 94 ARCHIVES PHYSICAL MED. & REHAB. 1851 (2013) (summarizing the state of clinical research on DOC, and asserting that late-term recovery from a DOC is not uncommon and that access to inpatient rehabilitation, which may be helpful, is problematic given healthcare policies).

83 FINS, RIGHTS COME TO MIND, *supra* note 9, at 82; Fins, *Conscious Burden*, *supra* note 29, at 138 ("Sometimes these episodic and early flashes of awareness go unnoticed or unappreciated by staff only to be the harbinger later of more robust recovery of communication function."); Giacino et al., *supra* note 7, at 109. As Professor Fins has described elsewhere,

There are additional challenges to diagnostic accuracy because of when the transition from VS to MCS occurs and where it takes place. At that juncture in their recovery, patients will likely have been transferred to chronic or long-term care and be in a setting of lesser medical acuity than the acute care hospital where definitive medical and surgical care was rendered. Because of the relative prestige and standing of these centers, physicians in chronic care may be hesitant to question the discharge diagnosis, even though a diagnostic revision would only reflect the ongoing biology of recovery and not represent an assessment error upstream in the provision of care.

Fins, *Minds Apart*, *supra* note 30, at 373; see also Fins, *Right to Care*, *supra* note 33, at 174 (reporting that acute-care practitioners may not appreciate upon discharge the potential for their patients to improve over time).

84 FINS, RIGHTS COME TO MIND, *supra* note 9, at 308; Fins, *Minds Apart*, *supra* note 30, at 382

with people at the end of life. This may be a distressing experience for these recovering patients who may not be able to communicate their distress.⁸⁵

Finally, these profoundly disabled persons are isolated and segregated from other conscious persons and from “mainstream medical care.”⁸⁶ If their consciousness were recognized, perhaps through wider use of the scientifically validated Coma Recovery Scale-Revised (CRS-R) by skilled examiners,⁸⁷ then patients in a MCS could be more fully integrated into society, which is a not only a desirable social goal, but also legally compelled.⁸⁸ Significantly, persons with MCS are denied full access to interpersonal relationships when they are not given the tools to help them communicate.⁸⁹ This leads to segregation, or what some have termed “neuronal segregation,”⁹⁰ which can cause both MCS patients and their families to suffer.

E. How the Injured Brain Is Similar to the Developing Brain

Recent scientific research has demonstrated that the injured brain is resilient and has the potential to recover to some degree after sustaining trauma.⁹¹ As Professor Fins has noted in a recent book, there is a

developmental capacity of injured brains to recover and regain ground, if properly assisted. Education for the young and rehabilitation for the brain injured are more closely linked if recovery from brain injury is viewed in a developmental frame. That is, an unfolding process that occurs as a process of an evolving biology from a new set point determined by the patient’s injury.⁹²

(describing how patients with DOC with the potential to recover are surrounded by those in active decline in nursing homes).

85 FINS, RIGHTS COME TO MIND, *supra* note 9, at 308.

86 *Id.* at 291, 298.

87 Giacino et al., *supra* note 72 (describing how the revised coma recovery scale can distinguish the MCS from the VS).

88 See American with Disabilities Act, 42 U.S.C. § 12101 (2012); *see also* G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities, art. 26 (Jan. 24, 2007) (emphasizing the rights of disabled individuals to be integrated into society through rehabilitative services); FINS, RIGHTS COME TO MIND, *supra* note 9, at 294 (“If individuals who might be able to communicate are denied the resources to do so, they are then denied access to being maximally integrated into society.”).

89 FINS, RIGHTS COME TO MIND, *supra* note 9, at 299.

90 *Id.* at 290-91.

91 Henning U. Voss et al., *Possible Axonal Regrowth in Late Recovery from the Minimally Conscious State*, 116 J. CLINICAL INVESTIGATION 2005 (2006).

92 FINS, RIGHTS COME TO MIND, *supra* note 9, at 306.

In both the young developing brain and in the injured recovering brain, there is new axonal growth (connections between neurons).⁹³ Both the young brain and the injured brain appear to share a common mechanism of axonal sprouting: the first as a developmental process, and the second as a regenerative one with new axonal connections between remaining neurons.⁹⁴

Education assists in the developmental process, and rehabilitation assists in the healing process.⁹⁵ In fact, those with brain injury often speak of their recovery in terms of “re-learning,” which supports the link between education of the developing brain and rehabilitation of the injured brain.⁹⁶ It may be instructive to think of rehabilitation of the injured brain as an educational intervention as much as a medical intervention. As Professor Fins has described elsewhere:

Both childhood education and brain injury rehabilitation are linked to developmental processes. Education is coupled with the progressively maturing brain, with curricula geared to what is cognitively and socially possible for young and developing minds. Brain-injury rehabilitation can be also understood as hinging upon a recuperative process that often retraces earlier developmental milestones. This recapitulation of an earlier process is made necessary by the setback of injury. Like the education of a child, brain injury rehabilitation’s purpose is to help an individual meet the progressive functional goals and to maximize one’s potential. If this premise is accepted, then rehabilitation is as important to the injured citizen as school is to the young child. In a Rawlsian frame, then, each provides the individual with the capabilities to maximize their participation in a shared democratic life.⁹⁷

Research findings from contemporary neuroscience supports this analogy.⁹⁸

93 *Id.*; Fins, *Lessons*, *supra* note 32, at 10; Randolph J. Nudo, *Recovery After Brain Injury: Mechanisms and Principles*, 7 *FRONTIERS HUM. NEUROSCIENCE* 887 (2013) (reviewing the literature on neuroplasticity).

94 *See* Nudo, *supra* note 93; Voss et al., *supra* note 91.

95 *See* FINS, *RIGHTS COME TO MIND*, *supra* note 9, at 306-07 (“Like the education of a child, brain injury rehabilitation’s purpose is to help an individual meet progressive functional goals and to maximize one’s potential . . .”).

96 *Id.*

97 Fins, *Minds Apart*, *supra* note 30, at 381.

98 Nudo, *supra* note 93, at 11 (“As a result of the abundance of evidence that has demonstrated that the brain is plastic after neuronal injury, and that behavioral experience can alter

As noted in a recent review article of neuroplasticity research, “Clues to understanding plasticity in adult brains can be found throughout the developmental neuroscience literature Though long-range axonal sprouting was once thought to be non-existent in adult animals, injury creates a particularly ripe environment for axonal sprouting processes to be re-initiated.”⁹⁹

Many persons could benefit from rehabilitation and other medical interventions. We confine our analogy of rehabilitation and education to medical conditions in which there is potential for the brain to heal in response to repeated “learning” exercises, which is similar to how a brain develops early in the life course in response to educational interventions. That is, persons with brain injury and subsequent DOCs are distinct in this way compared to someone with arthritis who may need access to drugs or physical therapy to treat their condition. The regenerative process that occurs in response to rehabilitation of the injured brain recapitulates the earlier developmental script, which is why the analogy to education early in the life course is especially apt.

II. IMPERATIVE TO PROVIDE REHABILITATION TO THE INJURED BRAIN

In this Part, we argue that it is ethically and legally imperative to provide rehabilitative technologies to patients with DOC. There are two bases for this assertion. Beyond respect for personhood, there is an ethical imperative to provide rehabilitation to the injured brain by analogy to the legally created expectation that children will be provided with free public education. Second, there is a statutory right to rehabilitation of the injured brain under the Americans with Disabilities Act and case law interpreting this Act. We conclude this Part by addressing objections to our arguments.

A. By Analogy to Expectation of Access to Free Public Education

1. Expectation of Access to Free Public Education

Education is a fundamental right in many countries, written into their constitutional text.¹⁰⁰ Education is also recognized as a right in international legal

neuronal structure and function in both healthy and injured brains, it is now clear that principles of neuroplasticity can form the foundation for a wide range of therapeutic approaches to recovery.”).

⁹⁹ *Id.*

¹⁰⁰ See Stephen Lurie, *Why Doesn't the Constitution Guarantee the Right to Education?*, ATLANTIC (Oct. 16, 2013), <http://www.theatlantic.com/education/archive/2013/10/why-doesnt-the-constitution-guarantee-the-right-to-education/280583> (describing how the United States is relatively unique in not guaranteeing such a constitutional right); see also Bert B. Lockwood et al., *Litigating State Constitutional Rights to Happiness and Safety: A Strategy for Ensuring the Provision of Basic Needs to the Poor*, 2 WM. & MARY BILL RTS. J. 1, 16, 23 (1993) (noting that

documents such as the International Covenant on Economic, Social and Cultural Rights (ICESCR), which the United States has not ratified.¹⁰¹ According to ICESCR, the reason that education is a fundamental human right is because education can aid in human development, dignity, respect for liberty, and participation in society.¹⁰² The text avers that the state-parties to the ICESCR

agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms. They further agree that education shall enable all persons to participate effectively in a free society, promote understanding, tolerance, and friendship among all nations and all racial, ethnic or religious groups, and further the activities of the United Nations for the maintenance of peace.¹⁰³

Whether education is a federal constitutional right in the United States has been litigated, and the Supreme Court answered in the negative in *San Antonio Independent School District v. Rodriguez*.¹⁰⁴ In this equal protection case about how public schools were financed in Texas, the Court stated:

Education, of course, is not among the rights afforded explicit protection under our Federal Constitution. Nor do we find any basis for saying it is implicitly so protected. As we have said, the undisputed importance of education will not, alone, cause this Court to depart from the usual standard for reviewing a State's social and economic legislation.¹⁰⁵

while the U.S. Constitution does not mention education explicitly, FDR's "Second Bill of Rights" included a right to education).

¹⁰¹ International Covenant on Economic, Social and Cultural Rights, *adopted* Dec. 16, 1996, 993 U.N.T.S. 3 (entered into force Jan. 3, 1976). While not binding on U.S. Courts, such documents may be used to help interpret the U.S. Constitution. *See, e.g.*, Susan H. Bitensky, *Theoretical Foundations for a Right to Education Under the U.S. Constitution: A Beginning to the End of the National Education Crisis*, 86 NW. U. L. REV. 550, 616-22 (1991). As Professor Bitensky notes, "The positive right to education as an international human rights norm has the potential to breathe a more complete and rational meaning into the language of these constitutional provisions." *Id.* at 622.

¹⁰² International Covenant on Economic, Social and Cultural Rights at 13.1.

¹⁰³ *Id.*

¹⁰⁴ 411 U.S. 1 (1973).

¹⁰⁵ *Id.* at 35.

Thus, the United States is unique among developed nations in not recognizing an affirmative constitutional right to education.¹⁰⁶

In response, many legal scholars assert that there is such a right.¹⁰⁷ Recent scholarship asserting that there is a positive constitutional right to education has argued that the right comes from substantive due process doctrine.¹⁰⁸ The Due Process clause of the Fourteenth Amendment has been the source of many

106 Lurie, *supra* note 100 (arguing that one of the reasons that the United States does not rank well in terms of education systems relative to other countries is because there is not a constitutional commitment to education and calling for a constitutional amendment, which he asserts will increase the cultural value placed on education, help improve U.S. education, and make America more globally competitive).

107 See, e.g., Bitensky, *supra* note 101 (identifying every possible source in the U.S. Constitution for a right to education, and asserting that none of the explicit rights have any meaning without education); Barry Friedman & Sara Solow, *The Federal Right to an Adequate Education*, 81 GEO. WASH. L. REV. 92 (2013); Daniel S. Greenspahn, *A Constitutional Right To Learn: The Uncertain Allure of Making a Federal Case out of Education*, 59 S.C. L. REV. 755 (2008); Areto A. Imoukhuede, *Education Rights and the New Due Process*, 47 IND. L. REV. 467 (2014); Edward Rubin, *The Affordable Care Act, the Constitutional Meaning of Statutes, and the Emerging Doctrine of Positive Constitutional Rights*, 53 WM. & MARY L. REV. 1639, 1715 (2012).

108 See, e.g., Friedman & Solow, *supra* note 107, at 96 (arguing that there is a right to “minimally adequate” public education under Due Process Clause); Greenspahn, *supra* note 107, at 773 (arguing that the 14th Amendment is the best source of such a right); Imoukhuede, *supra* note 107, at 470, 478, 491-92 (arguing that a right to education should be grounded in liberty-based arguments that emphasize dignity and the connection of dignity to education, rather than equality-based arguments that the court has been distancing itself from). Professor Bitensky also leads her analysis of a right to education under the Due Process Clause. Bitensky, *supra* note 101, at 579-96.

The Due Process Clause is especially important given that equal protection-based constitutional claims are difficult to win. Asserting an equal protection claim is unlikely to be successful in regards to education. See Imoukhuede, *supra* note 107, at 491-92.

Equal protection-based claims are also especially difficult to prevail with when they pertain to persons with disabilities who do not get special protections in the form of heightened scrutiny. Kenji Yoshino, *The New Equal Protection*, 124 HARV. L. REV. 747, 748, 758-59 (2011). Because persons with disabilities do not get heightened scrutiny, state action that treats them differently is more likely to be upheld. *Id.* at 755-56, 760. Professor Yoshino argues that equality claims are now brought under the Due Process Clause as “dignity” claims. *Id.* at 748-50. He argues that this legal trend can be considered a positive development because the government can respond to an equality-based claim by “leveling-down,” whereas they cannot with a liberty-based claim. *Id.* at 787. Some Supreme Court Justices dislike constitutional dignity claims, however. See, e.g., *Obergefell v. Hodges*, 135 S. Ct. 2584, 2639 (Thomas, J., dissenting) (“[T]he Constitution contains no ‘dignity’ Clause, and even if it did, the government would be incapable of bestowing dignity. Human dignity has long been understood in this country to be innate.”).

The Supreme Court has recently noted the connection between due process and equal protection. See, e.g., *Obergefell*, 135 S. Ct., at 2590 (“The Due Process Clause and the Equal Protection Clause are connected in a profound way. Rights implicit in liberty and rights secured by equal protection may rest on different precepts and are not always coextensive, yet each may be instructive as to the meaning and reach of the other.”). But see *Obergefell*, 135 S. Ct., at 2623 (Roberts, C.J., dissenting) (“Absent from this portion of the opinion, however, is anything resembling our usual framework for deciding equal protection cases.”).

unenumerated constitutional rights, such as the right to privacy.¹⁰⁹ One standard test for whether something is an implied or unenumerated liberty-based right is whether the right is grounded in history and tradition.¹¹⁰ Using this commonsense test, scholars assert that there is an established constitutional right to education because of the long history of compulsory education of children and adolescents, as well as the federal government's historical involvement in granting lands for public schools.¹¹¹

Regardless of what legal scholars assert or the presence of compulsory education across the nation, however, *Rodriguez* still stands, and the Supreme Court has not recognized a positive constitutional right to education. Instead, the Court has explicitly recognized only a negative right to education—that is, a right to be free from governmental interference in educational choices.¹¹² The Court hinted in *Rodriguez* that there might be some minimum level of education that is constitutionally protected, however, which leaves open the possibility of an eventual positive expansion of this right to one that is constitutionally sanctioned

109 See Friedman & Solow, *supra* note 107, at 107 (describing how judges agree that unenumerated rights exist). Substantive due process doctrine actually began in education-related cases. *Id.* at 119-20.

110 See, e.g., *Washington v. Glucksburg*, 521 U.S. 702, 720-21 (1997) (holding a fundamental right may exist if it is “objectively, deeply rooted in this Nation’s history and tradition” and “implicit in the concept of ordered liberty, such that neither liberty nor justice would exist if they were sacrificed”). More “liberal” Justices also look to evolving understandings of what constitutes a fundamental right. Friedman & Solow, *supra* note 107, at 108.

In the recent context of whether same-sex marriage is a fundamental right under the Due Process Clause, the *Obergefell* Court wrote of the substantive due process test:

Courts must exercise reasoned judgment in identifying interests of the persons so fundamental that the State must accord them its respect. History and tradition guide and discipline the inquiry but do not set its outer boundaries. When new insight reveals discord between the Constitution’s central protections and a received legal stricture, a claim to liberty must be addressed.

Obergefell, 135 S. Ct. at 2589. This new test was critiqued by Chief Justice Roberts, who dissented from this opinion:

Allowing unelected federal judges to select which unenumerated rights rank as “fundamental”—and to strike down state laws on the basis of that determination—raises obvious concerns about the judicial role. Our precedents have accordingly insisted that judges “exercise the utmost care” in identifying implied fundamental rights, “lest the liberty protected by the Due Process Clause be subtly transformed into the policy preferences of the Members of this Court.”

Id. at 2616 (Roberts, C.J., dissenting) (internal citations omitted).

111 Bitensky, *supra* note 101, at 586-90; Friedman & Solow, *supra* note 107, at 114-16, 127.

112 See Bitensky, *supra* note 101, at 563-64, 573, 580-81 (discussing early Supreme Court cases establishing this negative right).

and supported.¹¹³ The *Rodriguez* Court also opined on the importance of education, noting that

[c]ompulsory school attendance laws and the great expenditures for education both demonstrate our recognition of the importance of education to our democratic society. It is required in the performance of our most basic public responsibilities, even service in the armed forces. It is the very foundation of good citizenship. Today it is a principal instrument in awakening the child to cultural values, in preparing him for later professional training, and in helping him to adjust normally to his environment. In these days, it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education.¹¹⁴

While the Court framed the importance of education initially in terms of participation in democratic society, a view echoed by others,¹¹⁵ the Court also recognized other functions of education. For example, the Court noted the connection between education and employment, normal socialization, adjustment to one's environment, and success in life. It is these latter functions of education that are significant to our argument.

While there is no federal constitutional right to education, access to free public education is, at the very least, an expectation. This is especially so because there is a right to education at the state and local level.¹¹⁶ In most states, this right

113 *San Antonio Indep. Sch. Dist. v. Rodriguez*, 411 U.S. 1, 36 (1973) (refusing to concede that “some identifiable quantum of education is a constitutionally protected” right). Several legal scholars have also discussed this possibility. Bitensky, *supra* note 101, at 566-67, 573; Friedman & Solow, *supra* note 107, at 117-19; Greenspahn, *supra* note 107, at 769-72. Greenspahn in particular notes that the language leaves open this possibility and discusses how the purposes for refusing to find such a right in the *Rodriguez* case are no longer applicable, but he ultimately argues that it is unlikely a court would find such a right given that they are “de-constitutionalizing” schools. Greenspahn, *supra* note 107, at 775-79. Professor Bitensky also notes that in other cases, the Supreme Court describes education not as a right, but also not “merely some governmental ‘benefit’ indistinguishable from other forms of social welfare legislation.” Bitensky, *supra* note 101, at 568.

114 *Rodriguez*, 411 U.S. at 29-30 (quoting *Brown v. Board of Education*, 347 U.S. 483, 493 (1954)).

115 See, e.g., Bitensky, *supra* note 101, at 596-606 (describing the connection between participation in democracy and education).

116 Imoukhuede, *supra* note 107, at 492; James E. Ryan, *A Constitutional Right to Preschool?*, 94 CAL. L. REV. 49 (2006). Note that there is federal financing for and federal legislation about education, so there is a mixed federal-state system of and right to public education. See Friedman & Solow, *supra* note 107, at 142-43, 146-47 (describing how No Child Left Behind provides some funding for education, and federal spending on education has increased

is referenced in the state constitution.¹¹⁷ Additionally, every single state has set up a free public education system for children and adolescents, supported by local and state taxes, and compels attendance.¹¹⁸ Through litigation at the state level over the past several decades, the right to education has been defined as a right to “minimally adequate” rather than “equal” education.¹¹⁹

Given the legally created expectation of free public education for children and adolescents, along with a longstanding history of the provision of such education, there is an ethical obligation—if not a constitutional duty—to continue providing such education in order to meet citizens’ expectations. Indeed, this ethical obligation is particularly pronounced because education is so important for a functioning democratic society, as noted by the *Rodriguez* Court.¹²⁰

2. Rehabilitation of an Injured Brain Is Similar to Education of a Developing Brain

As discussed above,¹²¹ the rehabilitation of the injured brain is similar in many respects to the education of the developing brain. Just as the “first few years of life are crucial for cognitive development,”¹²² and early childhood education aids in this development, so is timely and consistent rehabilitation of the injured brain necessary for healing and “redevelopment” of the brain and restoration of brain function.

There is also reason to believe that the bipartisan political support for preschool would also exist for brain-injured persons with DOCs.¹²³ People

over time); Greenspahn, *supra* note 107, at 781-82 (describing how the majority of funding for education comes from the local and state level).

117 Friedman & Solow, *supra* note 107, at 116-17; Greenspahn, *supra* note 107, at 779-80; Ryan, *supra* note 116, at 53, 69 (noting that all state constitutions reference education in some way, but excepting seven states, all are silent as to the age at which public education is required).

118 Greenspahn, *supra* note 107, at 774, 781-82 (noting that school attendance is compulsory and noting that the source of funding for education is primarily states and municipalities).

119 After the *Rodriguez* decision, advocates for educational reform began bringing equal protection lawsuits at the state level, under the state constitutions. They had mixed success, losing more often than they won. They then started demanding “adequate” rather than “equal” education, and were much more successful. See Friedman & Solow, *supra* note 107, at 127-32; Greenspahn, *supra* note 107; Ryan, *supra* note 116, at 74.

120 *San Antonio Indep. Sch. Dist. v. Rodriguez*, 411 U.S. 1 (1973).

121 See discussion *supra* Section I.E.

122 Ryan, *supra* note 116, at 50 (arguing that this is, in part, why people widely support preschool).

123 *Id.* at 51 (“[T]he beneficiaries are a sympathetic and appealing group. One can hardly blame these young children for their own circumstances. They are as innocent and untainted as any group can be. Assisting children at this stage in their lives, to get them ‘on the right path,’ is an

support preschool so that children can have equality of opportunity, and because preschoolers need someone to provide them with education and care.¹²⁴ Similarly, brain-injured persons need provision of education and care. Both preschool and rehabilitation post-brain-injury are pivotal developmental periods.

3. If Understood as Education, Minimally Adequate Rehabilitation of Injured Brain Is Ethically Compelled

Given that rehabilitation of an injured brain can be thought of as similar to education of the developing brain, and given that there is a legally created expectation that the state will provide children, whose brains are developing, with education, we argue that rehabilitation of the injured brain should also be provided. Given the content of the state-level right to education is, at a minimum, the right to an “adequate” education, brain-injured persons with disorders of consciousness should receive “adequate” rehabilitation. This means that instead of being isolated in custodial care facilities, these patients should be given access to quasi-educational interventions that may aid them in realizing their post-injury potential. We recognize that this is a novel argument, and there is likely to be resistance to our assertions. Whatever one’s perspective, however, it is difficult to disagree with the premise that it is time to engage in a dialogue, accommodating ethical and legal challenges prompted by advances in neuroscience in diagnosis and treatment of DOCs.

Some may argue that because the legal expectation that persons will be provided with education is only extended to children aged five or six to around age eighteen, and not to adults,¹²⁵ our analogy is flawed because we are arguing for rehabilitation of injured *adult* brains. If, however, this expectation of education is conceived not based on chronology, but instead based on potentiality, our analogy survives. That is, if the purpose of education is not to educate children and adolescents, but instead the purpose of education is educate developing brains, which need education to reach their potential, then it makes

inherently attractive idea . . .”).

124 *Id.* People also support education for persons with disabilities, also because of a strong belief in equality of opportunity. This principle is embodied in the Individuals with Disabilities Education Act (IDEA), 20 U.S.C. §§ 1400-82 (2012). The IDEA promotes integrated education to the extent possible. Integration of persons with disabilities is important because segregation causes feelings of inferiority, as noted by the *Brown* Court. *Brown v. Board of Education*, 347 U.S. 483, 494 (1954) (“To separate [students] . . . because of their race generates a feeling of inferiority as to their status in the community that may affect their hearts and mind in a way unlikely to ever be undone.”).

125 This right has not been extended to preschool or college. Some have argued that there should be a constitutional right to preschool, but have stopped short of arguing for such a right to college. *See* Ryan, *supra* note 116, at 88-90.

sense that there should be an expectation of re-education of an injured brain, which has potential to more fully develop. *We do believe that the purpose of legally mandated free public education of children is based on potentiality rather than chronology*, and therefore assert that our analogy between education of developing brains and rehabilitation of an injured brain is proper. That is, persons with brain injury have a period post-injury in which they go through a developmental process similar to that of early life, which is why we advocate for rehabilitative resources during this window of opportunity.

Some may also argue that the primary purpose of free public education of children is to prepare them to participate in democratic society, and that given the uncertainty about persons with a DOC or in a MCS being able, in the future, to exercise their rights to free speech or to vote, the rationale for asserting there should be access to rehabilitation for an injured brain based on the legal expectation of access to a free public education is not applicable. To this criticism of our argument, we respond by pointing to the IDEA,¹²⁶ which applies to persons who may never fully participate in democracy.

The IDEA strives to ensure that children with disabilities are provided access to a free public education, tailored to their individual circumstances, regardless of their disability and independent of their capacity to fully participate as citizens.¹²⁷ In the “Findings” section of the IDEA, Congress states:

Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

Notably, while participation in society is mentioned as one reason for the policy of educating children with disabilities, so are reasons such as living independently and having equal opportunity. Even children who may never be able to fully participate in democratic society are guaranteed an education because of the importance of education for community participation and integration.¹²⁸

Similar to children with profound intellectual disabilities who may never be able to fully participate in democratic society, persons in a MCS may likewise

126 Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400-82 (2012).

127 *Id.* § 1400(d)(1)(A) (“The purposes of this title are to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living.”); *see also* FINS, RIGHTS COME TO MIND, *supra* note 9, at 307-08 (discussing the IDEA in the context of brain injury).

128 The IDEA provides for transition services to focus on outcomes such as community participation. *See id.* § 1401(34)(A).

not be able to fully participate. This possibility does not mean, however, that persons in a MCS should not be given rehabilitation, which may have other benefits, such as enhancing communication abilities, thus making it possible for them to be more integrated in society. Therefore, we assert that even given the uncertainty about the ability of persons in a MCS to fully participate in democratic society, there should be a recognized expectation to rehabilitation of the injured brain, a direct consequence of the nation's commitment to educating all persons and allowing them to develop to their full potential.

Given past and existing political support for preschool¹²⁹ and for educating children with disabilities,¹³⁰ and the similarity between educating the developing brain and rehabilitating the injured brain, we believe that government officials may be receptive to political advocacy on behalf of persons with DOC, urging access to rehabilitation.

B. By Statute and Case Law

This Section describes important legislation and jurisprudence that address disability rights, how lack of access to rehabilitation for persons with DOCs violates these laws and their purposes as currently written, what may be gained by a lawsuit under the ADA on behalf of persons with DOCs, and the role that considerations of cost plays in accommodating persons with disabilities.

1. Purpose of the Rehabilitation Act of 1973, ADA, ADAAA, and Olmstead

Some legal scholars argue that certain pieces of legislation actually interpret the Constitution and define positive rights that the Constitution failed to unenumerated.¹³¹ In particular, legislation can help define broad constitutional purposes such as liberty, equality, and a strong national government.¹³² It is through legislation that positive—rather than solely negative—rights may more legitimately be created.¹³³

This perspective on how legislation can and should aid in interpreting the Constitution may not be widely shared, especially by the Supreme Court Justices themselves.¹³⁴ However, even conservative Supreme Court Justices note the importance of major rights being created or announced through legislation rather than through the courts under a substantive due process, liberty-based analysis.

¹²⁹ See Ryan, *supra* note 116, at 49-50.

¹³⁰ See 20 U.S.C. § 1400(d)(1)(A).

¹³¹ See, e.g., Rubin, *supra* note 107, at 1694.

¹³² *Id.* at 1669.

¹³³ *Id.* at 1668 (arguing that the next step in realizing the Constitution's main purposes is to recognize positive rights)

¹³⁴ *Id.* at 1693-94.

This perspective was reaffirmed in the strongly worded dissents in the recent *Obergefell* decision,¹³⁵ lamenting that the Court decided that gay marriage was a right instead of allowing the country to come to this outcome through a democratic process.¹³⁶

Whether one views the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) of 1990, or the Americans with Disabilities Act Amendments Act (ADAAA) of 2008 as interpreting constitutional values or being policy decisions enacted by democratically elected politicians, these pieces

135 See, e.g., *Obergefell v. Hodges*, 135 S. Ct. 2584, 2620 (2015) (Roberts, J., dissenting) (“Our cases have consistently refused to allow litigants to convert the shield provided by constitutional liberties into a sword to demand positive entitlements from the State.”); *id.* at 2631 (Thomas, J., dissenting) (“Since well before 1787, liberty has been understood as freedom from government action, not entitlement to government benefits.”).

136 See e.g., *id.* at 2642 (Alito, J., dissenting) (“The Members of this Court have the authority and the responsibility to interpret and apply the Constitution. Thus, if the Constitution contained a provision guaranteeing the right to marry a person of the same sex, it would be our duty to enforce that right. But the Constitution simply does not speak to the issue of same-sex marriage. In our system of government, ultimate sovereignty rests with the people, and the people have the right to control their own destiny. Any change on a question so fundamental should be made by the people through their elected officials.” (quoting *United States v. Windsor*, 133 S. Ct. 2675, 2715-16 (2013))).

Law professors have made similar observations as the dissenting justices in *Obergefell*. For example, Professor Rubin notes that some believe that courts should not be asserting positive rights, which is a policy decision best left to legislatures, which are accountable to the people in ways that unelected federal judges are not. See Rubin, *supra* note 107, at 1706-07, 1710. Even when judges do assert positive rights, they still often nod to the importance of the legislature in asserting them. See, e.g., *Obergefell*, 135 S. Ct. at 2591 (“While the Constitution contemplates that democracy is the appropriate process for change, individuals who are harmed need not await legislative action before asserting a fundamental right.”); see also *id.* at 2605 (majority opinion) (“Of course, the Constitution contemplates that democracy is the appropriate process for change, so long as that process does not abridge fundamental rights.”).

Liberal Justices would also prefer that social change occur through other branches of government. For example, Professor Bagenstos notes that Justice Ginsburg thinks that social change through the courts should be incremental and accomplished in tandem with other branches of the government. See Samuel R. Bagenstos, *Justice Ginsburg and the Judicial Role in Expanding “We the People”*: *The Disability Rights Cases*, 104 COLUM. L. REV. 49, 50, 56-59 (2004) (“[C]ourts could not make broad-scale social change alone but must do so in dialogue with more representative, participatory institutions of government.”). The reason for this is described well by Chief Justice Roberts in his *Obergefell* dissent:

When decisions are reached through democratic means, some people will inevitably be disappointed with the results. But those whose views do not prevail at least know that they have had their say, and accordingly are—in the tradition of our political culture—reconciled to the result of a fair and honest debate. In addition, they can gear up to raise the issue later, hoping to persuade enough on the winning side to think again By deciding this question under the Constitution, the Court removes it from the realm of democratic decision.

Obergefell, 135 S. Ct. at 2625 (Roberts, C.J., dissenting).

of legislation send a clear and strong message about the U.S. government's attitude toward the disabled population. The purpose of this legislation, particularly the ADA and ADAAA, is to ensure the full participation of persons with disabilities in society; to prohibit discrimination against persons with disabilities; and to prioritize integration of persons with disabilities into their communities instead of encouraging or permitting their isolation and segregation.¹³⁷

While the Rehabilitation Act of 1973¹³⁸ was focused on aiding individuals with disabilities in gaining employment,¹³⁹ it also recognized the importance of the goals of independence and self-sufficiency even for those for whom employment would not be possible.¹⁴⁰ The ADA focused more broadly than on employment, extending section 504 of the Rehabilitation Act, which referenced nondiscrimination, giving its intent more bite.¹⁴¹ As noted by Professor Cook, the

137 As the ADA states, "[T]he Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals." 42 U.S.C. § 12101(a)(7) (2012).

138 Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355 (codified as amended in scattered sections of 29 U.S.C. §§ 700-796).

139 *Id.* § 100(A) ("The purpose of this title is to authorize grants to assist States to meet the current and future needs of handicapped individuals, so that such individuals may prepare for and engage in gainful employment to the extent of their capabilities."); *Id.* § 400(a)(3) ("In carrying out his duties under this Act, the Secretary shall . . . promote the cause of the rehabilitation of handicapped individuals and their greater utilization in gainful and suitable employment.").

140 The Rehabilitation Act notes this in various places in the 1973 text, such as:

The purpose of this Act is to provide a statutory basis for the Rehabilitation Services Administration, and to authorize programs to . . . (3) conduct a study to develop methods of providing rehabilitation services to meet the current and future needs of handicapped individuals for whom a vocation goal is not possible or feasible so that they may improve their ability to live with greater independence and self-sufficiency."

Id. at § 2(3).

"The Secretary shall conduct a comprehensive study . . . to assist individuals with the most severe handicaps who, due to the severity of their handicaps or other factors such as their age, cannot reasonably be expected to be rehabilitated for employment but for whom a program of rehabilitation could improve their ability to live independently or function normally within their family and community.

Id. at § 130(a)(2).

141 *Id.* at § 504 ("No otherwise qualified handicapped individual in the United States, as defined in section 706, shall, solely by reason of his handicap, be excluded from the participation in or be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.").

Writing about section 504 of the Rehabilitation Act, Professor Cook asserted:

ADA's findings section "make[s] it plain as it could be that the primary evil addressed in the ADA was the segregation that continues to impose an isolated, denigrated existence upon persons with disabilities."¹⁴² The ADA was intended as

"As a remedy for segregated public services, the Rehabilitation Act and its contemporaneously enacted regulation have been practically a dead letter Adults with disabilities seeking access to integrated residential and community services have fared little better. Appellate courts, ignoring substantial section 504 arguments, have permitted government agencies to confine and isolate persons with disabilities in remote institutions, nursing homes, and other segregated facilities When it comes to the segregation of persons with disabilities, federal compliance officers have largely turned their heads."

Timothy M. Cook, *The Americans with Disabilities Act: The Move to Integration*, 64 TEMP. L. REV. 393, 394-96 (1991). Thus, "[i]n the ADA, Congress determined, as apparently did the Executive, that section 504 simply was not working as a means of eradicating discrimination and segregation in this country." *Id.* at 416. Cook asserted that the blind, deaf, and persons with mobility disabilities were more successful in 504 claims, but not those segregated in "isolated settings." *Id.* at 396.

In *Olmstead v. L.C. ex rel. Zimring*, the Supreme Court also recognized the evolution of protection for persons with disabilities over time. 527 U.S. 581, 599 (1999) ("The ADA stepped up earlier measures to secure opportunities for people with developmental disabilities to enjoy the benefits of community living."). Unlike earlier legislation like the Rehabilitation Act, the ADA asserts that segregation of persons with disabilities is discrimination. *Id.* at 600.

142 Cook, *supra* note 141, at 398. Polling done just a few years prior to the passage of the ADA showed that the disabled were much less likely than the non-disabled to attend events in their communities. See Robert L. Burgdorf, Jr., "Equal Members of the Community": *The Public Accommodations Provision of the Americans with Disabilities Act*, 64 TEMP. L. REV. 551, 554-55 (1991). The reasons they cited were not feeling welcome and also barriers to participation (such as architectural barriers). *Id.* This means that they are highly isolated relative to other persons. *Id.*

Cook also draws a connection between state-sponsored segregation of the disabled with state-sponsored segregation based on race. Cook, *supra* note 141, at 404-07.

Congress made it plain in the ADA's legislative history that it believed the evils of segregation by race to be the same as the evils of segregation by disability. Congress regarded *Brown* as an equally important basis for eradicating disability segregation as it had been in striking down classifications based on race.

Id. at 410. He cites the statements of several members of Congress that linked segregation based on race to that based on ability status. *Id.* at 410 n.120. In both cases, segregation causes harm, and is a violation of civil rights. Importantly, however, the courts have not recognized disability to be a suspect class, receiving higher scrutiny in Equal Protection cases, and so the ADA becomes very important in protecting the civil rights of persons with disabilities. For a discussion of courts' "deferential standard of review to state-imposed classifications based upon disability," and how Congress responded by raising the standard of review by enacting the ADA, see *id.* at 433-34, 438. In fact, Congress modeled language in the ADA after language in the 1964 Civil Rights Act, which in Cook's view shows that Congress intended discrimination on the basis of disability to be taken as seriously as discrimination on the basis of race. *Id.* at 438-39.

Other scholars have also focused on the connection between the civil rights movement and the

“a comprehensive piece of civil rights legislation [that] promises a new future: a future of inclusion and integration, and the end of exclusion and segregation.”¹⁴³

disability rights movement. *See, e.g.*, FINS, RIGHTS COME TO MIND, *supra* note 9, at 286-311; Bagenstos, *supra* note 136, at 51, 55.

Some have critiqued how the ADA was modeled after the Civil Rights Act of 1964, however. Bonnie Poitras Tucker, *The ADA's Revolving Door: Inherent Flaws in the Civil Rights Paradigm*, 62 OHIO ST. L.J. 335, 342-43 (2001) (arguing that the ADA should instead have been based on “human” rights principles). Tucker writes, “As a civil rights law the ADA purports to require equal treatment for people with disabilities. In recognition of the fact that equal treatment does not lead to inclusion in the mainstream for many people with disabilities, however, the ADA requires different treatment for people with disabilities.” *Id.* at 345. Tucker argues that unlike in the case of race, disability often requires affirmative action on behalf of or differential treatment toward the disabled (rather than “equal” treatment) in order to result in equal outcomes; that is, “reasonable accommodations” are “affirmative action.” *Id.* at 354. Tucker notes that “[s]ince equal treatment of people with disabilities often leads to unequal results, different treatment is required to ensure equivalent results.” *Id.*

Tucker also discusses the differences between discrimination on the basis of race (often intentional and active) and that based on disability (often passive). *Id.* at 363-64. She writes that “[t]he more frequent scenario concerning different treatment of people with disabilities involves not the deliberate, affirmative exclusion from programs or activities, but the passive failure to provide affirmative assistance to make inclusion possible.” *Id.* at 364. This again makes the modeling of the ADA after the Civil Rights Act of 1964 problematic, since while action can be race-neutral, it cannot really be disability-neutral given that disability is a relevant difference in how one is treated. *Id.* at 365-66.

143 Cook, *supra* note 141, at 425 (quoting H.R. REP. NO. 101-485, pt. 3 at 26 (1990)). As an example of the excitement with which disability advocates viewed the ADA, see the following assessment just after its passage:

The Americans with Disabilities Act (“ADA”) is a landmark piece of legislation guaranteeing the civil rights of forty-three million Americans with disabilities. The ADA is the most significant civil rights legislation since the Civil Rights Act of 1964. Its enactment will profoundly change the legal rights of individuals with disabilities. The ADA points toward a future in which its promise of civil rights will join existing programs of financial support to create meaningful equality of opportunity for disabled individuals.

Nancy Lee Jones, *Overview and Essential Requirements of the Americans with Disabilities Act*, 64 TEMP. L. REV. 471, 471 (1991). *But see* Mary Johnson, *Before Its Time: Public Perception of Disability Rights, the Americans with Disabilities Act, and the Future of Access and Accommodation*, 23 WASH. U. J.L. & POL’Y 121, 136-37 (2007) (discussing how the actual ADA is not exactly civil rights legislation). Johnson writes:

After the revisions, the bill read less like a true civil rights law than a strange hybrid based on the understanding our national legislators and their staffs had about disability law. It was based on the understanding that disability law was a kind of benefits-based legislation that gave something to a group of people—like Social Security, disability benefits, or rehabilitation services, services that you only got if you qualified as disabled. . . . Disability was still viewed as a medical problem making one incapable of working (and, with a doctor’s okay,

Such integration would often require modifications and auxiliary aids and services, unless providing such accommodations would be an undue hardship or fundamentally alter a program.¹⁴⁴

Although Congress originally enacted the ADA in 1990, Congress amended it in 2008 in legislation entitled Americans with Disabilities Amendments Act (ADAAA), in response to courts limiting protection for the disabled in a way Congress had not intended.¹⁴⁵ Congress stated:

[I]n enacting the Americans with Disabilities Act of 1990 (ADA), Congress intended that the Act “provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities” and provide broad coverage [T]he holdings of the Supreme Court . . . have narrowed the broad scope of protection intended to be afforded by the ADA, thus eliminating protection for many individuals whom Congress intended to protect.¹⁴⁶

Congress responded by rejecting the Supreme Court’s narrow interpretation of disability¹⁴⁷ and clearly affirming commitment to the original purposes of the

entitled to benefits) when the ADA was enacted. Disability rights activists had conceived it as a civil rights law, but almost nobody else understood what ‘civil rights’ could possibly mean when it came to disabled people.

Id. at 136-38. This lack of understanding extended to judges who viewed the ADA as “a form of public benefit program for people with disabilities rather than a mandate for equality.” *Id.* at 139 (quoting Matthew Diller, *Judicial Backlash, the ADA and the Civil Rights Model*, 21 BERKELEY J. EMP. & LAB. L. 19, 23 (2000)). Disability advocates wanted the ADA to be treated as an antidiscrimination statute rather than as an entitlement program. *Id.* at 141.

144 Cook, *supra* note 141, at 428, 430. For a critique of how the ADA provides exceptions for cost or business considerations unlike other civil rights legislation, see Johnson, *supra* note 143, at 123, 127 (“The ADA is a civil rights act with an economic loophole built in: it says if assuring rights of access cost too much they do not have to be granted.”).

145 Some scholars have argued that courts limited the promise of the ADA because they were uncomfortable with the affirmative action required by this piece of legislation. See, e.g., Tucker, *supra* note 142.

146 Americans with Disabilities Amendments Act of 2008, Pub. L. No. 110-325, § 2(a)(1), (4), 122 Stat. 3553, 3553 (quoting 42 U.S.C. § 12101(b)(1) (2012)).

147 *Id.* at § 12101(b). For a discussion of how the ADAAA modified the ADA, see Alex B. Long, *Introducing the New and Improved Americans with Disabilities Act: Assessing the ADA Amendments Act of 2008*, 103 NW. L. REV. COLLOQUY 217. Professor Long describes how the ADA was a disappointment in the employment context because the Supreme Court narrowly construed “disability.” *Id.* at 217-18. The ADAAA was amended to reject this narrow definition. *Id.* at 219-21.

Johnson argues that the reason the courts did not find for disabled plaintiffs under the original

ADA.

The history of disability rights legislation is one of increasing protection for those with disability. The ADA extended the Rehabilitation Act's nondiscrimination protections to cover entities that do not receive federal funds.¹⁴⁸ The ADAAA expanded upon the ADA to broaden the definition of disability. Despite these expansions, there are still gaps in the legislation. For example, there are still significant questions about what constitutes reasonable accommodations or modifications. These terms are not defined in either the ADA or the ADAAA, and when the courts address the issue, the cases tend to be too fact-specific to act as precedent.¹⁴⁹ To date, neither legislation nor case law addresses what reasonable accommodations or modifications are for persons with DOCs.

Olmstead is the leading Supreme Court case interpreting the Title II of the ADA as promoting integration of the disabled into mainstream society when possible.¹⁵⁰ The ADA explicitly asserts that segregation of the disabled is a form

version of the ADA was because they did not fully understand the principles of the ADA. She asserts that the reason judges did not understand the principles is that the legislation was passed based on the lobbying of disability rights activists who did not also lobby the public or the media, explaining the reasons disability rights legislation was needed. Johnson, *supra* note 143, at 121-22. She contrasts the ADA with other civil rights legislation, which was publicly discussed; unlike the Civil Rights Act of 1964, most Americans did not know about the ADA. *Id.* at 123. Another reason why Congress's intent was not implemented was because of the backlash to the ADA that played out in the press, stating that unlike other pieces of civil rights legislation that just prohibited action, the ADA required affirmative obligations that were costly ("special benefits"). *Id.* at 130-31; *see also* Tucker, *supra* note 142, at 337-40 (arguing that the ADA was passed before Americans were ready to accept its principles and there has thus been backlash). The way to limit the ADA was to limit to whom the ADA applied, and thus the definition of disability was limited. Johnson, *supra* note 143, at 132. *But see* Stephen L. Mikochik, *The Constitution and the Americans with Disabilities Act: Some First Impressions*, 64 TEMP. L. REV. 619, 624-25 (1991) (asserting that the ADA was discussed and debated over years at both the federal and state government level and thus "did not steal upon unsuspecting states"); *see also* Jones, *supra* note 143, 472-75 (describing the lengthy process of passage of the ADA). While Johnson appears to fault disability rights activists for not making their case for the passage of the ADA to the press, one could just as easily fault journalists for failing to cover the proposed legislation.

148 Johnson, *supra* note 143, at 126; Jones, *supra* note 143, at 475-76 ("A key rationale used to support the ADA was that it essentially extended into the private sector an existing federal statute.").

149 Long, *supra* note 147, at 228 ("[T]he few times the Supreme Court has addressed the concept of reasonable accommodation or reasonable modification, the cases have been so fact specific as to provide little guidance for future cases."); *see also* Jones, *supra* note 143, at 479.

150 Writing for the Court, Justice Ginsburg stated:

[W]e conclude that, under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate,

of discrimination, which the legislation seeks to eliminate.¹⁵¹ Writing for the Court, Justice Ginsburg noted the connection between segregation of persons with disabilities in institutions and discrimination:

Recognition that unjustified institutional isolation of persons with disabilities is a form of discrimination reflects two evident judgments. First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice.¹⁵²

Although *Olmstead* specifically considered whether the institutionalization of those with intellectual disabilities was a violation of Title II of the ADA, its reasoning about isolation and segregation and the connection to discrimination

the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.

Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581, 607 (1999).

For a discussion of the limitations of *Olmstead*, see David Fergeler, *The Constitutional Right to Community Services*, 26 GA. ST. U. L. REV. 763 (2009-10). Fergeler focuses on the lack of definition for key terms in the Court's qualified holding. He argues that by not providing precise definitions, states have latitude to keep persons with intellectual disabilities in institutions for no rational reason. *Id.*

¹⁵¹ See Cook *supra* note, 141, at 399-414 (describing a history of state-sponsored segregation of persons with disabilities). But see *Olmstead*, 527 U.S. at 623 (Thomas, J., dissenting) ("At bottom, the type of claim approved of by the majority does not concern a prohibition against certain conduct (the traditional understanding of discrimination), but rather imposition of a standard of care."); see also Tucker, *supra* note 142 (discussing how the Justices are uncomfortable with the reality that eliminating discrimination requires affirmative action in the case of disability).

¹⁵² *Olmstead*, 527 U.S. at 600-01 (internal citations omitted).

similarly applies to those in a MCS and to Title III of the ADA.¹⁵³ The assumptions of “incapable” and “unworthy” point to an assessment of the potentiality of persons with a DOC, particularly those in the MCS.¹⁵⁴ Their potentiality is unknown, however, if there are no rehabilitative interventions. These brain-injured but conscious persons are assumed to be unable to participate in society, and so are segregated in custodial care, with diminished quality of life. They are also not integrated into the community because they are not given access to functional communication (referring generally to neuroprosthetics and rehabilitative technologies).¹⁵⁵ Failure to provide this is unlawful discrimination.¹⁵⁶

2. How Lack of Access to Rehabilitation for Those in MCS Violates the ADA and Olmstead

The minimally conscious are profoundly disabled, and because of this are covered by existing disability rights legislation and court cases interpreting such legislation.¹⁵⁷ Title I of the ADA is likely not applicable to most persons in an

153 Some have argued that *Olmstead* will have an impact beyond the issue of deinstitutionalization. See, e.g., Bagenstos, *supra* note 136, at 55. This case is often referred to as the “*Brown v. Board of Education* of the disability rights movement.” *Id.* at 49. The reasons for drawing this connection between the cases are twofold, according to Bagenstos:

First, the direct holding of the case squarely attacked a practice that the disability rights movement had long mobilized against: the isolation of individuals with disabilities in congregate institutions separate from the community at large. To disability rights activists, that practice of segregation bore a striking resemblance to the Jim Crow practices attacked by the African American civil rights movement. Second—and perhaps more important—the *Olmstead* opinion marked the Court’s most expansive endorsement of the disability rights movement’s broad conception of discrimination and of its goal of integrating people with disabilities throughout the fabric of community life.

Id. at 55 (internal citations omitted).

154 *But see* Nakase-Richardson, *supra* note 55 (demonstrating that a significant proportion of this population regain functional capacity).

155 See *supra* Sections I.B, I.D, and II.A.3; see *infra* Section II.B.2. As Professor Fins has argued, linking patients to functional communication is a holy grail toward connecting people to their family and community. FINS, RIGHTS COME TO MIND, *supra* note 9, at 292-94.

156 It is important to note that while the legislation seeks to eliminate discrimination, which has many negative effects on the wellbeing of persons with disabilities, the legislation is also promoting integration, which has many positive effects on the quality of life for persons with disabilities. This is a two-pronged approach towards improving the status of the disabled. See Cook, *supra* note 141, at 455 (discussing the benefits of integration).

157 Persons with DOC meet all of the statutory requirements for disability. They have both physical and mental impairments, and these impairments substantially limit major life activities. Americans with Disabilities Act, 42 U.S.C. § 12102(1)(A) (2012) (defining disability); see Jones, *supra* note 143 (summarizing what each Title of the ADA of 1990 covers).

MCS because it relates to employment,¹⁵⁸ of which persons in a minimally conscious state are not capable. Title II may be relevant for some persons in a MCS as it concerns governmental-provided services.¹⁵⁹ Title III of the Act, however, is highly relevant as it prohibits discrimination by private entities providing public accommodations.¹⁶⁰ Hospitals and health care providers are covered in this section.¹⁶¹

Equal access to public accommodations has long been seen as a civil right.¹⁶² Title III notes that it is discrimination under the ADA if there is

[a] failure to take such steps as may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the entity can demonstrate that taking such steps would fundamentally alter the nature of the good, service, facility, privilege, advantage, or accommodation being offered or would result in an undue burden.¹⁶³

The ADA further mandates that “[g]oods, services, facilities, privileges, advantages, and accommodations shall be afforded to an individual with a disability in the most integrated setting appropriate to the needs of the individual.”¹⁶⁴ Federal regulations have expanded on these requirements.¹⁶⁵

¹⁵⁸ 42 U.S.C. § 12111.

¹⁵⁹ 42 U.S.C. § 12131.

¹⁶⁰ 42 U.S.C. § 12182(a) (“No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation.”). This section covers prohibited activities such as unequal benefit or separate benefit, and also encourages integration.

Prior to the ADA, “[a] privately owned place of public accommodation, prohibited by federal law from discriminating against people on the basis of race, religion, or national origin, was not legally deterred from engaging in blatant and invidious discrimination against people with disabilities.” Burgdorf, *supra* note 142, at 556. For a detailed summary of Title III of the ADA and what it requires, see Burgdorf, *supra* note 142.

¹⁶¹ 42 U.S.C. § 12181(7)(F).

¹⁶² Burgdorf, *supra* note 142, at 552-53. Given this, such access is guaranteed in the Civil Rights Act of 1964 and also the ADA. *Id.* at 553.

¹⁶³ 42 U.S.C. § 12182(b)(2)(A)(iii).

¹⁶⁴ 42 U.S.C. § 12182(b)(1)(B).

¹⁶⁵ Americans with Disabilities Act Title III Regulations: Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities, 28 C.F.R. pt. 36.303 (2016). The regulations titled “Auxiliary aids and services” states in first section:

- (a) General. A public accommodation shall take those steps that may be necessary to ensure that no individual with a disability is excluded, denied

While neuroprosthetics are not mentioned in the statute or regulations, they fall under the catchall provision in both the statute and the regulations about required auxiliary aids and services, entitled “[o]ther similar services and actions.”¹⁶⁶ “Scholars have recognized that “the specific requirements [of the ADA’s reasonable accommodation requirements] may vary as technological advances occur.”¹⁶⁷

The reason auxiliary aids and services must be provided is “to ensure effective communication with individuals with disabilities.”¹⁶⁸ As the regulations note:

The type of auxiliary aid or service necessary to ensure effective communication will vary in accordance with the method of communication used by the individual; the nature, length, and complexity of the communication involved; and the context in which the communication is taking place. A public accommodation should consult with individuals with disabilities whenever possible to determine what type of auxiliary aid is needed to ensure effective communication, but the ultimate decision as to what measures to take rests with the public accommodation, provided that the method chosen results in effective communication. In order to be effective, auxiliary aids and services must be provided in accessible format, in a timely manner, and in such a way as to protect the privacy and independence of the individual with a disability.¹⁶⁹

Guidance accompanying the regulations states that “[i]mplicit in this duty to provide auxiliary aids and services is the underlying obligation of a public

services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the public accommodation can demonstrate that taking those steps would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations being offered or would result in an undue burden, i.e., significant difficulty or expense.

Id. In the examples section, the regulations focus on auxiliary aids and services for the deaf or hard of hearing, the blind or low vision, and have a catchall provision “Other similar services and actions.” *Id.*

¹⁶⁶ Compare 42 U.S.C. § 12103(1)(D) (adopting this catchall category), with 28 C.F.R. § 36.303(b)(4) (same).

¹⁶⁷ Jones, *supra* note 143, at 495.

¹⁶⁸ 28 C.F.R. § 36.303(c).

¹⁶⁹ *Id.* § 36.303(c)(1)(ii).

accommodation to communicate effectively with customers, clients, patients, companions, or participants who have disabilities affecting hearing, vision, or speech.”¹⁷⁰ The statute, regulations, and interpretive guidance imply that healthcare providers have a legal obligation to provide aids and services (such as the rehabilitative technologies previously discussed) in order to assist persons with DOCs in communicating with their treatment providers and caregivers. Indeed, lack of such aids and services is likely to lead to substandard care, although this has not been litigated in the courts. If patients with a DOC are actually minimally conscious and can experience pain, but are not given access to the tools to communicate with their healthcare provider, this is, in our view, a violation of the ADA and, more importantly, simply inhumane.¹⁷¹

Notably, “auxiliary aids” do not have to be the most technologically advanced or expensive—they just have to result in effective communication with the person with a disability.¹⁷² In the context of patients in a MCS, this may mean

170 Department of Justice, Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities, 28 C.F.R. pt. 36, app. A, at 133 (2010) (providing guidance for ADA Title III Regulations).

171 Palliative care and tending to pain relief is important for seriously ill patients. See JOSEPH J. FINS, *A PALLIATIVE ETHIC OF CARE: CLINICAL WISDOM AT LIFE’S END* (2006) (describing barriers to palliative care, and the need to plan for palliative care); Robert A. Burt, *The Supreme Court Speaks—Not Assisted Suicide but a Constitutional Right to Palliative Care*, 337 NEW ENG. J. MED. 1234 (1997) (arguing that *Washington v. Glucksburg* requires states to not obstruct the provision of palliative care).

172 The ADA Title III Regulations state under “alternatives” that

[i]f provision of a particular auxiliary aid or service by a public accommodation would result in a fundamental alteration in the nature of the goods, services, facilities, privileges, advantages, or accommodations being offered or in an undue burden, i.e., significant difficulty or expense, the public accommodation shall provide an alternative auxiliary aid or service, if one exists, that would not result in an alteration or such burden but would nevertheless ensure that, to the maximum extent possible, individuals with disabilities receive the goods, services, facilities, privileges, advantages, or accommodations offered by the public accommodation.

28 C.F.R. § 36.304(g). The accompanying guidance states:

As the Department noted in the preamble to the NPRM, the list of auxiliary aids in section 36.303(b) is merely illustrative. The Department does not intend that every public accommodation covered by title III must have access to every device or all new technology at all times, as long as the communication provided is effective.

28 C.F.R. pt. 36, app. A, at 115. Further guidance states:

The Department understands that there are many new devices and advances in technology that should be included in the definition of available auxiliary aids .

that entities providing treatment or care may choose to provide access to a communication board (or similar low-cost communication device)¹⁷³ or to drugs in a first attempt at low-cost but effective communication. If these interventions do not result in effective communication, however, then hospitals and custodial care facilities may be required under ADA Title III to provide access to neuroimaging to aid in effective communication with the patient in the MCS.¹⁷⁴

We assert that when persons in a MCS are segregated into “custodial care” and not provided access to auxiliary aids or services that may assist them in communicating with their treatment providers, that this violates the ADA and *Olmstead*.¹⁷⁵ This lack of integration is discrimination under the ADA, and violates the very purpose of the statute.¹⁷⁶ Moreover, patients with DOCs are not just receiving segregated services, but often are not receiving services at all, and instead are just institutionalized.

While Justice Kennedy in his *Olmstead* concurrence notes that “segregation and institutionalization are [not] always discriminatory,”¹⁷⁷ we assert that in the case of minimally conscious persons receiving custodial care rather than inpatient rehabilitation, this is a form of discrimination under the ADA and is unlawful under the logic of the majority’s *Olmstead* opinion.¹⁷⁸ The lack of access to

. . . While much of this technology is not expensive and should be available to most title III entities, there may be legitimate reasons why in a particular situation some of these new and developing auxiliary aids may not be available, may be prohibitively costly (thus supporting an undue burden defense), or may otherwise not be suitable given other circumstances The Department recognizes that the available new technology may provide more effective communication than existing technology and that providing effective communication often will include use of new technology However, the Department has not mandated that title III entities make all technology or services available upon demand in all situations.

Id. at 122. This is in context of technology for deaf or hard of hearing individuals, but is just as applicable to those with a DOC. *See also* Dalia B. Taylor, *Communicating with Vegetative State Patients: The Role of Neuroimaging in American Disability Law*, 66 STAN. L. REV. 1451, 1468-69 (2014) (describing this guidance as applied to this population).

173 *See, e.g.*, SPEAK YOUR MIND FOUNDATION, *supra* note 58 (describing low-cost communication devices for persons with severe brain injury).

174 *See* Taylor, *supra* note 172, at 1471-83 (analyzing whether a court would find that access to brain scanning for persons with DOC would be considered an auxiliary aid under the ADA, and arguing that this claim would likely succeed).

175 FINS, RIGHTS COME TO MIND, *supra* note 9, at 296-305.

176 *Id.*

177 *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 614 (1999) (Kennedy, J., concurring); *see also id.* at 607 (Stevens, J., concurring) (emphasizing that it is “unjustified institutional isolation” that is discrimination under the ADA).

178 *Id.* at 600-01, 607 (majority opinion).

rehabilitative technologies that fall under the category “auxiliary aids and services” also violates Title III of the ADA.

3. Legal Remedies Available to Persons with DOCs Under the ADA

Because the existence of the MCS has only been recently recognized, and because persons in a MCS are often isolated in custodial care, there has not been a disability rights movement around consciousness.¹⁷⁹ In fact, application of the ADA to this group has only recently been discussed in the legal literature.¹⁸⁰ Professor Fins began the call for a legal remedy for these individuals in 2010.

Instead, it is respect and regard for civil rights and the more fundamental issue that conscious individuals, who might be embraced more fully by our shared human community, are routinely ignored, sequestered, and segregated. This is an utter breach of their inalienable rights, rights that in this case may be dependent upon the provision of interventions, which remain experimental but will likely be expensive and scarce. Because of this it is important to view this technology as enabling a fundamental right to be enjoyed by all citizens, a class utterly dependent upon the goodwill of others, and their recognition of their reciprocal ethical obligation to provide access to technology that will restore their voice and given them more equal opportunities. If these responsibilities are not recognized by our common morality, they should be enforced by law.¹⁸¹

However, the ADA can provide remedies for persons in a MCS who are isolated and segregated, without access to rehabilitation, which may aid in their communication and subsequent community integration. Lawsuits brought under

179 Fins, *RIGHTS COME TO MIND*, *supra* note 9, at 302, 304, 310 (arguing that persons with DOCs are not seen as disabled, and instead are seen as sick or nearly dead, and so do not have protections of others persons with disabilities). Furthermore, the families of those with DOCs are “too burdened by caregiving to engage in the social action necessary to initiate and sustain a social movement.” They are instead spending their time fighting for appropriate, quality care for their disabled family member. *Id.* at 310; *see also* Fins, *Minds Apart*, *supra* note 30, at 380 (describing how in comparison to advocates of those with intellectual disabilities, “no comparable political prowess exists for advocates of those with disorders of consciousness”)

180 *See e.g.*, FINS, *RIGHTS COME TO MIND*, *supra* note 9, at 302 (“Until now, to my knowledge, no one has made an ADA claim for this population.”); Fins, *Minds Apart*, *supra* note 30, at 377. Professor Fins’ argument predated by a few years an argument that would be made by a Stanford Law School student who argued for a right to neuroimaging devices under the ADA for those with DOC. *See* Taylor, *supra* note 172.

181 Fins, *Minds Apart*, *supra* note 30, at 377.

the ADA may lead to injunctive relief.¹⁸²

[I]njunctive relief shall include an order to alter facilities to make such facilities readily accessible to and usable by individuals with disabilities to the extent required by this subchapter. Where appropriate, injunctive relief shall also include requiring the provision of an auxiliary aid or service, modification of a policy, or provision of alternative methods, to the extent required by this subchapter.¹⁸³

In this case, advocates for the minimally conscious and those with other DOC that may progress to a MCS¹⁸⁴ may sue for access to rehabilitation while in custodial care, which can be construed as an “auxiliary aid”¹⁸⁵ so that they can be integrated into the community.¹⁸⁶

As the Guidance for the 2010 regulations of the ADA note, “When a public accommodation ignores the communication needs of the individual requiring an auxiliary aid or service, it does so at its own peril, for if the communication provided is not effective, the public accommodation will have violated title III of the ADA.”¹⁸⁷ Litigation on behalf of a patient in a MCS may have lasting social change.¹⁸⁸ Successful litigation would provide notice to hospitals and physicians

182 For a critique of this sole remedy, see Johnson, *supra* note 143, at 128. She describes how in political compromises to get the ADA of 1990 passed, the section on damages was dropped. *Id.*

183 Americans with Disabilities Act, 42 U.S.C. § 12188(a)(2) (2012).

184 But, currently “[n]o advocacy group specifically addresses the needs of patients with disorders of consciousness.” Fins, *Minds Apart*, *supra* note 30, at 380.

185 See *supra* notes 163-175 and accompanying text.

186 Taylor, *supra* note 172, argues that the Rehabilitation Act and the ADA may require hospitals to provide neuroimaging to persons with DOC, but does not broaden her argument to rehabilitation generally, which would also include access to drugs and other neuroprosthetics. She predicts that “[c]ourts may have to determine whether these federal auxiliary aid requirements obligate hospitals and other health care facilities to provide neuroimaging technology as a mode of communication for otherwise uncommunicative or vegetative state patients.” *Id.* at 1454. She suggests that “[r]epresentatives of vegetative state or minimally conscious state patients could one day take advantage of these Acts to sue for injunctions mandating that health care facilities provide brain-scanning technology as a means of communication.” *Id.* at 1465. For a discussion of standing issues related to plaintiffs with DOC, see *id.* at 1466-67.

187 Department of Justice Guidance, 28 C.F.R. pt. 36, app. A, at 118. Additionally, the guidance recommends ongoing communication assessments of a person with a disability due to changing needs. *Id.* (“This dialogue should include a communication assessment of the individual with a disability initially, regularly, and as needed, because the auxiliary aids and services necessary to provide effective communication to the individual may fluctuate.”).

188 For a brief review of factors that indicate whether “litigation will affect social change,” see Ryan, *supra* note 116 at 90. Writing in the context of whether litigation would be successful in creating a right to preschool, Ryan noted:

that the ADA applies to those with DOCs, which may lead to prioritizing an accurate diagnosis for those with a DOC and to providing access to rehabilitative technologies to aid in communication, in an attempt to avoid costly lawsuits.

Widespread medical change with respect to DOCs is to be preferred to litigation, which is a lengthy process, during which time the person or class of persons with DOCs may suffer irreparable harm including death, illness, or an impaired quality of life because of inadequate access to medical and rehabilitative interventions. Furthermore, there is a risk that litigation may not be successful, if defendants prevail on available defenses under the ADA, by, for example, claiming that rehabilitative technologies pose an “undue burden” on the provider. Changes in medical practice could be accelerated, however, if there first were successful litigation under the ADA.

As one of us previously argued, “Access to neuroprosthetic technologies, drugs, and devices that might restore functional communication cannot be viewed as a mere entitlement to be funded or cut, a benefit to be shaved in a tight budget year, or a service at the margins.”¹⁸⁹ This is not only so because to deny such access is profoundly unethical, but also because it violates the mandates of the ADA and *Olmstead*.

Importantly, however, we are not arguing that all persons with DOCs should be given rehabilitation or moved out of custodial care. As the *Olmstead* majority noted, “We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or

[S]cholars have identified a set of factors that make it more or less likely that litigation will affect social change. These factors include: the intensity of opposition; whether legislators and administrators view court orders as helpful political cover for leveraging more resources for programs they already favor; whether market mechanisms will help implement the newly created right; the ease with which rulings can be evaded; and the determination, resources, and strategies of those seeking to enforce the right.

Id. In the case of a right to rehabilitative technologies for patients with a DOC, we do not foresee opposition except perhaps from those concerned with costs or for those who think the right to die may be threatened. Legislators do support integration of persons with disabilities, and a court ruling may provide political cover if such integration increases costs, which may not be as popular with constituents. There is a market for technological interventions that may aid in integrating persons with DOCs in society. If there is sustained attention to the issue of integration, court rulings mandating access to rehabilitation cannot be evaded. The final factor may be the one that is most problematic for advocates of patients with DOC. They may not have the time to sustain their legal challenge and to pursue lasting social change outside of their individual remedy. On the whole, however, we think litigation could affect social change for this population.

189 Fins, RIGHTS COME TO MIND, *supra* note 9, at 294.

benefit from community settings.”¹⁹⁰ For those with recent injuries and who are still in a coma, rehabilitation may not be appropriate. For those in a VS, rehabilitation may not be appropriate (it may, however, if it could assist them in recovering consciousness to some degree). Rehabilitation would clearly be ineffective in a patient properly diagnosed as being in a permanent vegetative state. However, given the rates of misdiagnosis, it is ethically and clinically imperative that, before patients are categorized as permanently unconscious, that this classification is vetted and appropriate. Furthermore, the diagnosis may only be ascertained, and the degree of the patient’s true function only understood, through interventions such a drug trial with agents like amantadine or zolpidem or speech or physical therapy, which might elicit findings that could critically upgrade their diagnostic state from the VS to MCS. Thus, it necessary to conduct a proper assessment to determine whether someone is actually in a permanent vegetative state¹⁹¹ prior to discharging a patient to chronic care rather than rehabilitation.¹⁹²

4. Counterarguments and Rebuttals

The most significant objection to recognizing a right to rehabilitation for the brain-injured person with a DOC under the ADA is that the provision of such rehabilitation may be cost-prohibitive or difficult to implement. In other words, providing access to rehabilitative technologies for persons with DOCs may constitute an “undue burden,” which is an available defense under the ADA for not providing a particular accommodation.¹⁹³ We will also address cost in a later

190 *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 583; *see also id.* at 610 (Kennedy, J., concurring) (“It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that the States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision [I]f the principle of liability announced by the Court is not applied with caution and circumspection, States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition.”); *see also* Bagenstos, *supra* note 136, at 58 (“One might regard these qualifications as improperly diluting the right to integration that was at stake in *Olmstead*. But it is possible to see them, instead, as a recognition of the limited capacity of courts to shoulder the burden of significant social change on their own.”). *But see* Cook, *supra* note 141, at 442-45 (arguing that all persons with disabilities should receive services in the community). In the case of DOCs, deinstitutionalization is not solely about social change, but is also about the ability of persons with DOC to be in the community.

191 Some patients may be thought to be in a permanent vegetative state, but are actually in a nonbehavioral MCS. FINS, RIGHTS COME TO MIND, *supra* note 9, at 131-33 (summarizing research on nonbehavioral MCS).

192 *Id.* at 93-95 (describing the role of McKesson Health Solutions, LLC’s InterQual Criteria in denying rehabilitation to patients in a DOC who could potentially benefit from such care).

193 28 C.F.R. § 36.303(a) (2016) (defining “undue burden” as “significant difficulty or expense”).

Section,¹⁹⁴ but will assert here that many of the rehabilitative technologies discussed in this paper are unlikely to be an undue burden on the entity providing public accommodations.¹⁹⁵

Given this particular population of persons with disabilities and where they are housed, it would likely not be an undue burden to provide them with rehabilitative technologies given that healthcare facilities should reasonably have them on hand if patients are in a venue appropriately suited to their rehabilitative needs.¹⁹⁶ It remains a question whether the custodial care facilities in which many persons with DOCs are living have the actual resources to provide appropriate rehabilitative technologies. But even in facilities that do not have access to the emerging technologies referenced here, they should provide cheaper, readily available alternatives such as access to communication boards, drugs, and the services of neurorehabilitative specialists.¹⁹⁷

Whether one agrees that the ADA is wise social policy, it is law and must be followed. The enacting legislature of the ADA intended for persons with disabilities to be fully integrated in society and a subsequent legislature amended the legislation to be stronger than courts had originally interpreted the ADA. As Justice Marshall noted in his partially concurring opinion in *City of Cleburne v. Cleburne Living Center*, a case about a zoning ordinance that prevented a group home for the intellectually disabled from being located at a certain site:

Courts, however, do not sit or act in a social vacuum. Moral philosophers may debate whether certain inequalities are absolute wrongs, but history makes clear that constitutional principles of equality, like constitutional principles of liberty, property and due process, evolve over time; what once was a ‘natural’ and ‘self-evident’ ordering later comes to be seen as artificial and invidious constraint on human potential and freedom. Shifting cultural, political, and social patterns at times come to make past practices appear inconsistent with fundamental principles upon which American society rests, an inconsistency legally cognizable under the Equal Protection Clause. It is natural that evolving standards of equality come to be embodied in legislation. When that occurs, courts should look

194 See discussion *infra* Section III.3.

195 Of course, this would become a moot point if such rehabilitative interventions were covered by insurers. See discussion *infra* Section III.1.

196 See Taylor, *supra* note 172 (arguing that the “undue burden” defense would not apply in most instances of requesting neuroimaging); see also Burgdorf, *supra* note 142, at 578 (discussing “undue burden” as it applies to small businesses); Fins et al., *supra* note 22.

197 See Burgdorf, *supra* note 142, at 580. The precise scope and nature of required services is within the domain of implementation science.

to the fact of such change as a source of guidance on evolving principles of equality.¹⁹⁸

We assert that the ADAAA of 2008 embodies evolving standards of equality in regard to persons with disabilities. If faced with a lawsuit that requests access to neuroprosthetics or other assistive devices for those with DOCs in order to aid them in communicating with their healthcare providers and caregivers and also to promote community integration, we argue that courts should find for the plaintiffs.

III. REFORMS TO REALIZE THE RIGHT TO REHABILITATION

Once a right to rehabilitation of the brain-injured minimally conscious patient is recognized—either as analogous to the expectation of free public education for children with developing brains or as a statutory right under the ADA—there must be legal and policy reforms. We have already noted the need for access to auxiliary aids and devices to assist in communication between the minimally conscious and their healthcare providers and caregivers, as mandated by the ADA. In this Part, we address some other necessary changes and objections to these changes. We do not address all possible reforms to realize the right to rehabilitation, including how our argument intersects with the Affordable Care Act, as that is beyond the scope of this Article.¹⁹⁹

A. Proposed Changes to Medicare Policies

Disability scholars have noted that rights alone are insufficient to achieve equality in the realm of disability. For example, Professor Bagenstos noted that Title I of the ADA, which prevents discrimination against the disabled in the context of employment, has not has the desired effect on increasing employment among persons with disabilities.²⁰⁰ This is because such a prohibition against discrimination does not address other structural barriers to employment such as

¹⁹⁸ 473 U.S. 432, 466 (1985) (Marshall, J., concurring in part and dissenting in part). Justice Kennedy echoes Justice Marshall's language on evolving standards of equality almost exactly in his recent *Obergefell* opinion. See text accompanying *supra* note 1.

¹⁹⁹.. We do not, for example, discuss many changes in medical practice that need to occur. One such change, for example, would be continued surveillance of those with DOC to determine whether they are minimally conscious. The legal implications of not surveilling such persons is that they are often institutionalized and placed under guardianship, which is a huge liberty infringement. If they are not routinely assessed for consciousness, this could constitute a violation of procedural due process. See Fergeler, *supra* note 150, at 799 (discussing this in the context of the institutionalization of the intellectually disabled.)

²⁰⁰ Bagenstos, *supra* note 136.

lack of access to healthcare, which is an entitlement.²⁰¹ His argument, in essence, is that the antidiscrimination elements of the ADA need to be combined with changes in social welfare programs.²⁰² As he notes in a recent *New York Times* commentary about the twenty-fi anniversary of the ADA, “[W]e will need not just antidiscrimination laws but social welfare programs that will overcome these barriers.”²⁰³

We also assert that the right to rehabilitation is insufficient to change the lived reality of persons with DOCs. There must also be changes to existing social welfare programs. One issue that patients with DOCs face are Medicare payment policies that may prevent them from receiving needed care. In a previous paper, we described how some groups of patients whose care was funded by Medicare alleged that they were subject to an “improvement” standard, meaning that they would not receive certain kinds of care if they were not expected to improve.²⁰⁴ If true, then this would violate Medicare’s policies; treatment and coverage decisions are supposed to be based on “medical necessity” rather than an improvement standard.²⁰⁵ These patients brought a class-action lawsuit against Medicare in *Jimmo v. Sebelius*.²⁰⁶ The parties ultimately settled when a judge refused to grant the government’s motion to dismiss, and the settlement resulted in negotiated changes to the Medicare Benefit Policy Manual between the plaintiffs’ counsel and the Centers for Medicare and Medicaid Services, explicitly noting that no patient should be subjected to such an improvement standard.²⁰⁷ The result of this settlement—the changes to the Medicare Manual—may have a ripple effect because many other payors use Medicare policies as a model.²⁰⁸

Patients with DOCs, given their severe disability, are often covered by Medicare,²⁰⁹ and thus changes due to the settlement apply to this group. If

201 *Id.*

202 *Id.*

203 Samuel Bagenstos, *Disability Laws Are Not Enough To Combat Discrimination*, N.Y. TIMES (July 26, 2015), <http://www.nytimes.com/roomfordebate/2015/07/26/the-americans-with-disabilities-act-25-years-later/disability-laws-are-not-enough-to-combat-discrimination> (writing in the context of employment, but the same is true for community integration in the case of persons with DOC).

204 Fins et al., *supra* note 22, at 182-183.

205 That is, care necessary to maintain or prevent decline should be covered, not just care that is expected to help patients improve. *See id.* at 183.

206 Amended Complaint, *Jimmo v. Sebelius*, No. 5:11-CV-17 (D. Vt. Oct. 25, 2011), 2011 WL 5104355.

207 *Jimmo v. Sebelius Settlement Agreement Fact Sheet*, CTRS. FOR MEDICARE & MEDICAID SERVS., <https://www.cms.gov/medicare/medicare-fee-for-service-payment/SNFPFS/downloads/jimmo-factsheet.pdf> (last visited on Oct. 1, 2016).

208 Fins et al., *supra* note 22, at 182.

209 Persons with disabilities are often insured through Medicare, Medicaid, or both. *See* Sandra M. Foote & Christopher Hogan, *Disability Profile and Health Care Costs of Medicare*

patients with DOCs were subjected to the alleged improvement standard, there is little doubt they would not meet such a standard. As a result, most would be denied care that may enable them to recover or at least “maintain” their present mental state and prevent further decline. So the *Jimmo* settlement could be considered a “win” for patients with DOCs. Unfortunately, however, “medical necessity” is still the Medicare standard, and it is difficult for patients with DOCs to demonstrate that inpatient rehabilitation is medically necessary. Moreover, simply being “maintained” in their current condition is not sufficient to trigger coverage of inpatient rehabilitation.²¹⁰

In our previous work, we have recommended changes to Medicare coverage policies that would be more appropriate for patients with DOC. As we noted:

We would propose expanding the definition of “reasonable and necessary” to include monitoring, rehabilitation, and therapy for MCS and view this heightened level of care as a new standard of care. This would include diagnostic, therapeutic, and rehabilitative interventions necessary to decrease diagnostic and prognostic error and maximize functional return of physical and cognitive capabilities, most notably the return of spoken language In addition to being dependent on skilled clinical care, MCS patients rely on access to a variety of drugs, devices, and diagnostic tools. This additional dependency needs to be understood within the settlement framework and the “reasonable and necessary” standard.²¹¹

B. Capabilities Approach

Expanding access to entitlements, such as in the case of our proposed Medicare changes, is not sufficient to ensure full inclusion in society for persons with DOC, but neither is the assertion of a right to rehabilitation or a right to community integration.²¹² Rather, it is a combination of entitlements grounded in rights, in particular access to resources and rehabilitative technologies that can

Beneficiaries Under Age Sixty-Five, 20 HEALTH AFF. 242, 245 ex.2 (2001).

²¹⁰ Fins et al., *supra* note 22, at 188.

²¹¹ *Id.* at 188-89.

²¹² Cf. Kaaryn Gustafson, Opinion, *More Work Needs To Be Done To Prevent Exclusion of the Disabled*, N.Y. TIMES (July 26, 2015), <http://www.nytimes.com/roomfordebate/2015/07/26/the-americans-with-disabilities-act-25-years-later/more-work-needs-to-be-done-to-prevent-exclusion-of-the-disabled> (“The A.D.A. was an important step in recognizing universal rights to dignity and inclusion among all Americans. But we have more work to do—and much of it requires a collective commitment to equality and inclusion, not just the hollow reverence we give to individual rights.”).

assist individuals in possibly achieving communication, that can help realize the right to not be segregated on the basis of disability.²¹³

For a better understanding of how to ensure the full dignity, equality, and liberty of persons with DOCs, we turn to the capabilities approach, which has been pioneered by Amartya Sen and Martha Nussbaum and recently expanded upon by Sridhar Venkatapuram in the specific context of health. This approach “asserts that societies should focus on supporting—nurturing, protecting, providing, expanding, restoring, and so forth—the capabilities of individuals to conceive, pursue, and revise their life plans” rather than focusing solely on outcomes.²¹⁴ Individual capabilities are sometimes defined as “freedoms or real opportunities to achieve beings and doings.”²¹⁵

Some scholars have identified what they consider to be core capabilities. For example, Nussbaum has a list of ten capabilities, including health; senses, imagination, and thought; and affiliation.²¹⁶ Recently, Venkatapuram has argued that the health capacity should be understood as a “meta-capacity,” which means it is necessary to exercise other capacities.²¹⁷ He defines the health capacity as “a person’s ability to achieve or exercise a cluster of basic capabilities and functionings, and each at level that constitutes a life worthy of equal human dignity in the modern world.”²¹⁸ When this and other necessary capabilities are

213 See FINS, RIGHTS COME TO MIND, *supra* note 9, at 292-94 (discussing the capabilities approach applied to persons with DOCs).

214 VENKATAPURAM, *supra* note 21, at 115 (citations omitted, summarizing work by Sen, Nussbaum, and others). Outcomes are also referred to as “functionings” or “achievements.” Nussbaum argues that the focus should be on a person’s capability rather than their achievements except when dignity is at stake. *Id.* at 135. Like Nussbaum, we would argue that if it is possible for a person with a DOC to communicate if given access to certain technologies, then we should focus on achievements or functionings rather than just capabilities because communication and community are central to human dignity. *Id.* at 135-36 (“Some functionings may be so valuable to maintaining minimal human dignity that they will not be allowed to be neglected or fail.”).

215 *Id.* at 117.

216 NUSSBAUM, *supra* note 20. With respect to persons with disabilities, Venkatapuram also describes how Nussbaum thinks that we should consider the needs of the severely disabled prior to setting up institutions rather than at the end of the process where only small accommodations can be made. VENKATAPURAM, *supra* note 21, at 150.

217 *Id.* at 143.

218 *Id.* Ensuring health capacity also requires considering and addressing the social determinants of health. As Venkatapuram argues:

The present argument for the CH pursues the line that the entitlement to each capability should be understood as the entitlement to the social bases of each causal component. And providing or supporting threshold levels of CH entails social action through influencing the social bases of the causal components of each capability. That is, protecting, promoting or restoring the CH of individuals to adequate levels is realized through the possible and justifiable interventions into personal features/needs, conversion skills, external physical conditions and surrounding social conditions.

not met—such as full participation in one’s social world—there is not equal dignity.²¹⁹

In the capabilities approach, resources are directed to ensure a particular capability, which may then lead to an achievement. In line with this approach, we focus on access to rehabilitative technologies for persons with DOCs as a capability intervention to aid in obtaining consciousness and in communication. This intervention can increase the capabilities of, for example, health and affiliation. We do not focus on whether persons with DOCs actually achieve consciousness and communication (which may be impossible), but on whether they have the equality of opportunity to do so. Often, this opportunity will only be available if they have access to the technologies we have described elsewhere in this Article.

The capabilities approach focuses on sufficiency or minimum freedoms.²²⁰ Like our earlier discussion of the legally created expectation of a free, public, minimally adequate education, and like our earlier discussion about the ADA not requiring the most technologically sophisticated or expensive auxiliary aids or devices but instead devices that permit effective communication, we likewise have confined our argument to the minimum rehabilitation necessary to help the brain-injured person with a DOC communicate. As we noted earlier, at least twenty-two percent of persons in a MCS will become fully independent, something only possible with intensive rehabilitation.²²¹ With low-cost interventions, many others may achieve some degree of independence, and at the very least, may be able to be integrated into their communities with increased ability to communicate.²²²

C. Counterarguments and Rebuttals

One compelling objection to our assertion that there is a right to rehabilitative technologies for brain-injured persons with DOC is one of timing. Some may argue that the issue of providing such access is not yet ripe given that many such technologies are currently in the investigational phase, and so may be of uncertain benefit. We assert, however, that because technology outpaces legal and societal responses, our argument is meant to be preemptive and proactive.

Id. at 156.

²¹⁹ *Id.* at 144.

²²⁰ *Id.* at 135.

²²¹ Nakase-Richardson et al., *supra* note 55. One of the issues is that there has not been enough research to know what the likelihood of success would be with this population if diagnosis was better, and if persons had access to all rehabilitative technologies as the standard of care.

²²² See, e.g., SPEAK YOUR MIND FOUNDATION, *supra* note 58 (describing various low-cost devices that assist in communication).

Thus, our argument should be understood as one for current scientific progress as well as an anticipatory argument for future scientific advances. It is never too early to consider the legal underpinning to support access to innovation and to anticipate changes in medical practice, especially when the consequence of neglecting these issues leads to a denial of civil and human rights. Indeed, without the legal argument, the work critical to bringing innovation to the standard of care might not be undertaken or accomplished.²²³ Scientific progress in this domain is moot without correlative access to these developments for patients.

Furthermore, receiving an accurate diagnosis is not an experimental intervention or an exploratory service, which are often not covered by private or public payors, but rather the standard of care for brain injury. An accurate diagnosis is what determines suitability for various rehabilitative interventions, and access to drugs, drug trials, and certain communication devices is part of an emerging standard of care for rehabilitating brain injuries.²²⁴ It may be the case, however, that patients with severe brain injury and subsequent disorders of consciousness will be discharged from the hospital to inpatient rehabilitation in order to perform a proper, in-depth diagnostic assessment.²²⁵

Similarly, some may also argue that by arguing for such access to what currently amounts, in some instances, to experimental interventions, we further the widespread therapeutic misconception that research is equivalent to treatment.²²⁶ It is important to note, however, that we are not arguing for special treatment for patients with DOCs, but parity²²⁷: we argue that patients should receive access to rehabilitative technologies that may assist them in regaining consciousness or communicating with their healthcare providers and family members.²²⁸

223 There is currently enough evidence to suggest efficacy for many of these interventions. See *supra* Section I.B. Furthermore, the dichotomy between research and treatment for this population should not be overstated. *Fins, Technology, supra* note 5, at 896.

224 Admittedly, access to rehabilitative technologies such as deep brain stimulation or communication through neuroimaging is not currently the standard of care for brain injury, but our argument anticipates when such technology may be part of the standard of care.

225 There is a large diagnostic error rate for patients with DOCs. Schnakers et al., *supra* note 70 (citing an error rate of 41 percent). Additionally, given that a patient's status may change over time from a VS to an MCS, even if initial neuropsychiatric testing does not indicate that patients have consciousness, they should be reassessed at a future date so that they are not segregated and isolated when they do have intermittent consciousness.

226 See Paul S. Appelbaum et al., *The Therapeutic Misconception: Informed Consent in Psychiatric Research*, 5 INT'L J.L. & PSYCHIATRY 319, 327-28 (1982) (reporting results of an empirical study of psychiatric patients' attitudes).

227 We address this issue in another paper. See Wright, Ulrich, & Fins, *supra* note 67.

228 We do acknowledge, however, that there is no longer a "simple dichotomy between research and clinical practice upon which so much of our normative and regulatory standards are founded." *Fins, Technology, supra* note 5, at 896; see also *supra* Section I.B. (describing the

Another strong counterargument for providing access to rehabilitative technologies for persons with DOC is cost, both social and economic.²²⁹ This objection or concern pertains both to the auxiliary aids required by the ADA to assist in communication and Medicare policy, as well as any other social welfare changes based on a right to rehabilitative technologies for patients with MCS. It is also a critique of the capabilities approach when phrased as an issue of whether society's goal should be spending a lot of money on a small number of individuals to achieve sufficiency instead of using that money on larger numbers of people to help them flourish, which can look like equalizing downward.²³⁰

In regards to ADA compliance, "Congress expressly determined that the costs of continued segregation of persons with disabilities were outweighed by the benefits of integration—on both an economic and a moral basis."²³¹ As Professor Tucker noted, "The underlying principle of the ADA is that people with disabilities must be fully integrated into society—that we must recognize the potential of *all* members of society, disabled or not, even though it may cost money or impose some burdens upon covered entities to reach this objective."²³²

While Congress determined that making the disabled productive would reduce costs,²³³ this rationale for integration may not apply for the minimally conscious.²³⁴ However, the moral imperative for integration still applies regardless of its cost,²³⁵ although healthcare facilities and providers who decline

evidence of efficacy for some interventions). Access to some interventions is now becoming part of an emerging standard of care. See John Whyte, *Disorders of Consciousness: The Changing Landscape of Treatment*, 82 NEUROLOGY 1 (2014).

229 See Cook, *supra* note 141, at 458.

230 See VENKATAPURAM, *supra* note 21, at 118-19, 137-39, 140-42 (describing critiques of the capabilities approach).

231 Cook, *supra* note 141, at 457.

232 Tucker, *supra* note 142, at 351.

233 Cook, *supra* note 141, at 458.

234 Indeed, Professor Tucker also asserts that the primary rationale of the ADA is to benefit the disabled, and any benefits to society at large through increased revenue from taxes, for example, are bonuses. See Tucker, *supra* note 142, at 350.

235 When describing the passage of the ADA, Professor Cook looks to the legislative history, which shows that political representatives were well aware of the economic costs of the legislation, but that the moral benefits outweighed those costs.

In the legislative history of the ADA, Congress acknowledged that, at least in the short run, the ADA would "impose considerable expenses and rightly so. It is time that we did these things. It is time that we brought persons with disabilities into full freedom, economic and otherwise, with other citizens in our society. This bill will do that. In doing so, we should be aware that it is going to be costly and difficult and that there will be some complaints."

Cook, *supra* note 141, at 464 (quoting Senator Hatch)).

to provide access to rehabilitative technologies for persons with a DOC may defend themselves against a claim under the ADA by arguing that such provision poses an “undue burden.”²³⁶

In regards to changing Medicare policies, which may trigger other healthcare insurers to change their policies, it is an open question as to whether costs will actually increase. While many may point to increased costs in providing physical rehabilitation or neuroimaging, which may have uncertain benefits, they fail to consider that patients with DOCs already incur great costs for health payors, costs that our proposed interventions may actually reduce.²³⁷ Importantly, however, we echo others who have noted that “[a]s issues relating to areas such as insurance and technology are explored, there will also be a financial cost to

236 See also Taylor, *supra* note 172, at 1480-83 (analyzing costs under the ADA and *Olmstead*). In the *Olmstead* opinion, cost was cited as a factor to consider when determining if a particular accommodation for a disabled person would fundamentally alter a state’s program. One way to think about cost is the cost of providing care in a restrictive institution compared to the cost of providing care in a less restrictive institution. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 594-95 (1999). Another way to think about cost, however, and the way the majority asserts is the proper way is to think about costs of providing care to the disabled in relation to the state’s overall program of providing care to persons with disabilities. *Id.* at 597, 603-06.

But we recognize, as well, the States’ need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States’ obligation to administer services with an even hand In evaluating a States’ fundamental-alteration defense, the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the States’ obligation to mete out those services equitably.

Id. at 597. The Court continued:

Sensibly construed, the fundamental-alteration component of the reasonable-modifications regulation would allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities.

Id. at 604.

237 See FINS, RIGHTS COME TO MIND, *supra* note 9, at 301-02 (offering an example of a proper cost-benefit analysis); see also Joseph J. Fins, *Deep Brain Stimulation: Calculating the True Costs of Surgical Innovation*, 12 VIRTUAL MENTOR 114 (2010) (arguing that there are huge costs to custodial care for persons with severe brain injury and DOC, and that experimental interventions such as DBS may actually reduce these costs due to offsetting benefits from the DBS; suggesting that by invoking cost arguments to reject interventions for those with DOC is part of systemic bias against those with severe brain injury). Professor Fins has also expressed concern in other work that fears about high costs of technology for neuroscience and treatment of neuropsychiatric disorders may inhibit such research and treatment. See, e.g., Fins, *Technology*, *supra* note 5, at 902.

support those evolving rights.”²³⁸ We assert that the ethical imperative of providing access to communication, which will aid in decreasing segregation and isolation and make integration into community possible, is a social good that far outweighs any monetary costs that may result from changing insurance policies.

CONCLUSION

Writing in the context of same sex marriage, Justice Kennedy recently stated, “[N]ew dimensions of freedom become apparent to new generations.”²³⁹ This is true in the context of disability rights as well. A reflection upon disability law is especially apt at this moment, given that it has been 25 years since the Americans with Disabilities Act of 1990 was passed.²⁴⁰ There has been a new generation of experience with the ADA and a new generation of developments in neuroscience that have expanded the category of disabled and also have expanded available auxiliary aids and services. Thus, there has been ample time for “new dimensions of freedom to become apparent.”

Disability law has evolved over time to emphasize and facilitate maximum community integration for persons with disabilities. Scholars have long noted the “expressive” or “pedagogical” effect of laws,²⁴¹ and in the case of the ADA, the law expresses our aspiration that all persons be part of society and have opportunities to achieve their full potential. As Ben Mattlin observed recently about the ADA in the *New York Times*, it is “about more than ramps and Braille; it’s about dispelling stereotypes, ensuring parity and fairness, creating opportunities and opening up our society to the full spectrum of types and needs. It’s about accepting, even welcoming, a huge and often marginalized segment of the population.”²⁴²

As Professor Fins and others have noted, there is a deep connection between rights and the capability to exercise these rights.²⁴³ In the context of disability, integration is not solely about living in one’s community, but also about having access to “auxiliary aids and services” that will aid in communication. This ability to communicate is vital to any meaningful sense of community

²³⁸ Jones, *supra* note 143, at 496.

²³⁹ *Obergefell*, 135 S. Ct. at 2588.

²⁴⁰ See *The Americans with Disabilities Act, 25 Years Later*, N.Y. TIMES (July 26, 2015), <http://www.nytimes.com/roomfordebate/2015/07/26/the-americans-with-disabilities-act-25-years-later> (debating the impact of the ADA 25 years after it was passed).

²⁴¹ Bitensky, *supra* note 101, at 635-637; see Cass R. Sunstein, *On the Expressive Function of Law*, 144 U. PA. L. REV. 2021, 2024-25 (1996).

²⁴² Ben Mattlin, *An Act That Enabled Acceptance*, N.Y. TIMES (July 25, 2015), <http://www.nytimes.com/2015/07/26/opinion/sunday/an-act-that-enabled-acceptance.html>.

²⁴³ FINS, RIGHTS COME TO MIND, *supra* note 9, at 292-94 (describing the connection between rights, capabilities, communication, and communities).

participation and inclusion.²⁴⁴

Given recent knowledge about a new class of disabled persons—those with minimal consciousness, a category based on new findings that did not exist when the ADA was originally conceived and passed—we need a new paradigm of community integration. In this Article, we have argued that access to rehabilitative technologies such as neuroprosthetics or pharmacological interventions is necessary to fulfill legal mandates of integration rather than segregation, which is a form of discrimination according to the ADA. As technology and medical science advance, the law needs to keep pace in order to be responsive to new realities. In this case, healthcare providers need to recognize that the ADA applies to patients with a DOC. While the ADA does not mention neuroprosthetics, these clearly fall within the definition of “auxiliary aid” and should thus be provided to persons in a MCS.

We have also argued that such access to rehabilitative technologies is compelled if rehabilitation of the injured brain is viewed as analogous to education of the developing brain, given that children have an expectation of free public education. The purpose of both interventions is the same—to provide beneficial stimulation to a brain that still has much developmental potential and is at a critical point in neurodevelopment. Furthermore, finding a right to rehabilitation of the injured brain based on the expectation of free public education protects against the weakness of statutory rights—the fact that statutes can be amended or revoked.²⁴⁵ As others have noted, “a comprehensive legal theory embodying both constitutional and statutory rights is more likely to serve private and public needs than a theory including just one or the other.”²⁴⁶

Importantly, however, while the right to rehabilitative technologies that will assist in communication is afforded to those with DOCs under the ADA or by analogy to the expectation of a free public education for children, this right may need to be realized through affirmative litigation. Successful realization of these rights may also require accompanying policy changes. Advocates for the

244 Indeed, when writing about group homes for persons with intellectual disabilities, Justice Marshall noted a connection between liberty and community when he stated that “what makes for human freedom and fulfillment—the ability to form bonds and take part in the life of a community.” *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 462 (1985) (Marshall, J., concurring in part and dissenting in part).

245 See Tucker, *supra* note 142, at 388 (“Congress might be more apt to lessen protections granted by the ADA rather than to increase those protections.”). When Congress did amend the ADA in 2008, however, it tried to strengthen protections for persons with disabilities.

246 Fergeler, *supra* note 150, at 779. Writing in the context of intellectual disabilities and institutionalization, Fergeler argues that institutionalization is a violation of procedural and substantive due process and asserts that the institutionalized should be considered a quasi-suspect class for purposes of equal protection analysis. *Id.* Fergeler then argues that institutionalization is rarely rational for purposes of the equal protection analysis even if the intellectually disabled are not treated as a suspect class. *Id.*

minimally conscious should use all available means—petitioning the courts, lobbying the legislature, and educating the medical profession—to achieve the goal of integrating persons with a DOC into their communities to the extent possible.

The problem of segregating the minimally conscious and those who have the potential to recover consciousness to some degree may have been hidden or unrecognized prior to the refinement of the category of DOCs and the development of drugs and devices that can help patients with DOCs.²⁴⁷ Now that we have proper diagnostic categories, are developing treatments for DOC, and are acutely aware that this class of patients has been isolated and segregated, we are obligated legally and ethically to address and overcome their isolation and segregation.²⁴⁸ The liberty, equality, and dignity of these disabled citizens with DOCs are at stake, as is their reintegration into our community.

247 Both the existence of the MCS and interventions for it have been enabled by rapidly changing technology. For a discussion of the relationship between neuroethics and technology, see Fins, *Technology*, *supra* note 5.

248 As the founder of Speak Your Mind Foundation, Dan Bacher, argues, persons with disabilities deserve devices that help them communicate. Speaking about one person in particular, he stated,

They deserve it. Maggie has the right to communicate, just as you or I would . . . [\$30] glasses enable her to interact with the world. Why wouldn't we do that? . . . [These devices] enable many, many others like Maggie to communicate effectively, to express their personalities, to control their environments, to speak their minds.

SpeakYourMind Found., *SpeakYourMind Foundation*, YouTube (Mar. 23, 2014), <https://www.youtube.com/watch?v=oRBPjUOrbd0> (quoted material occurs between 4:00 and 4:15 as well as 5:45 and 5:55); *see also* FINS, RIGHTS COME TO MIND, *supra* note 9, at 301 (describing low-cost communication technologies).

An Evidence-Based Objection to Retributive Justice

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Abstract:

Advancements in neuroscience and related fields are beginning to show, with increasing clarity, that certain human behaviors stem from uncontrolled, mechanistic causes. These discoveries beg the question: If a given behavior results from some combination of biological predispositions, neurological circumstances, and environmental influences, is that action unwilled and therefore absolved of all attributions of credit, blame, and responsibility? A number of scholars in law and neuroscience who answer “yes” have considered how the absence of free will should impact criminal law’s willingness to justify punishments on the basis of retribution, with some arguing that criminal law ought to dispense with retributive justice because the concept of blameworthiness is out of touch with scientific reality. This Note posits a more practical reason for reform by reviewing available empirics on the way people perceive human agency. The research suggests that as the science of human agency becomes increasingly vivid and reductionistic, laypeople will become proportionally less willing to attribute blame, and these shifting societal intuitions will ultimately diminish criminal law’s moral credibility. The practical effects of low moral credibility might include diminished compliance, cooperation, and acquiescence with criminal laws, as well as increased general deviance. Importantly, this Note observes that these effects will likely manifest even if people retain a belief in free will. Further, ontological reality plays no part in this Note’s argument; whether we in fact have free will is irrelevant. This Note instead contributes to the discourse by highlighting the implications of oncoming shifts in lay conceptions of both particular behaviors and the natural world writ large.

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TABLE OF CONTENTS

TABLE OF CONTENTS.....	290
INTRODUCTION.....	291
I. REFORM VS. CONSERVATION: THE CURRENT STATE OF THE DISCOURSE	298
A. FREE WILL’S PLACE IN CRIMINAL LAW	299
B. THE DEBATE: REFORMIST ARGUMENTS AND CONSERVATIONIST RESPONSES	303
C. THIS NOTE’S ROLE IN THE DISCOURSE.....	306
II. MORAL CREDIBILITY: THE PRACTICAL EFFECTS OF PERCEIVED INJUSTICE	308
III. A LOOMING MORAL CREDIBILITY PROBLEM.....	311
A. FOLK INTUITIONS: FACTS AND DETERMINANTS.....	312
B. THE NEW SCIENCE OF HUMAN AGENCY	318
C. BRINGING IT ALL TOGETHER: TWO DIMMERS AND A FLIP SWITCH.....	321
CONCLUSION	323

INTRODUCTION

“All theory is against the freedom of the will; all experience for it.”¹ Samuel Johnson’s centuries-old aphorism captures the core free will problem in a choice few words—that is, that although our decisions and actions truly feel willed, a scientific worldview presupposes that every event is wholly the product of mechanistic, observable causes that seem to preclude a transcendent moment of agency.² Despite its elegance, Johnson’s aphorism invites the same pejorative question as the free will debate writ large: who cares? Although laypeople are largely aware of the fate-versus-free-will distinction and have their own views on human agency,³ the meat of this debate, like so many other topics in ontology and metaphysics, can be criticized as “unreal, impractical, or unimportant.”⁴ Aside from the occasional news article⁵ or television program,⁶ daily life rarely prompts people to ponder whether their actions are willed or determined by a complex matrix of past causes (an ontological theory called “determinism”),⁷ and the arguments of the philosophers and theorists who do take the question seriously seem to echo in the closed loop of academia, not a legislative hall. Thus, the word “theory” in Johnson’s aphorism may carry an unintended descriptive load: the free will debate is too conceptual to change the way we conceptualize, engage with, and structure our society.

Recent discoveries in neuroscience, genetics, biology, and the behavioral sciences, however, have shaken the dust off the free will debate and thrust it into the popular fore by painting vivid pictures of the causal mechanisms that drive us

1 PAUL SHELDON DAVIES, *SUBJECTS OF THE WORLD; DARWIN’S RHETORIC AND THE STUDY OF AGENCY IN NATURE* 137 (2009) (quoting JAMES BOSWELL, *THE LIFE OF SAMUEL JOHNSON* 291 (1924)).

2 *See id.* at 139.

3 *See* Emad H. Atiq, *How Folk Beliefs About Free Will Influence Sentencing: A New Target for the Neuro-Determinist Critics of Criminal Law*, 16 *NEW CRIM. L. REV.* 449, 474-75 (2013) (reporting the results of studies showing that people tend to think human decisions are “undetermined by prior causes” and that our “universe [is] indeterministic rather than deterministic”).

4 John L. Hill, Note, *Freedom, Determinism, and the Externalization of Responsibility in the Law: A Philosophical Analysis*, 76 *GEO. L.J.* 2045, 2045 (1988).

5 *See, e.g.*, David Eagleman, *The Brain on Trial*, ATLANTIC (June 7, 2011, 4:58 PM), <http://www.theatlantic.com/magazine/archive/2011/07/the-brain-on-trial/308520/>; Tania Lombrozo, *Blame Your Brain: The Fault Lies Somewhere Within*, NPR (June 16, 2014, 2:30 PM), <http://www.npr.org/blogs/13.7/2014/06/16/322556750/blame-your-brain-the-fault-lies-somewhere-within>; Dennis Overbye, *Free Will: Now You Have It, Now You Don’t*, N.Y. TIMES (Jan. 2, 2007), <http://www.nytimes.com/2007/01/02/science/02free.html>.

6 Jim Fallon, *Exploring the Mind of a Killer*, TED (July 16, 2009), https://www.ted.com/talks/jim_fallon_exploring_the_mind_of_a_killer/transcript?language=en.

7 *See* Hill, *supra* note 4, at 2049 (defining determinism).

to act.⁸ Whereas past studies on uncontrolled determinants of human behavior were largely correlational,⁹ new research on the neurological, genealogical, and endocrinal underpinnings of conscious decisionmaking have illuminated an increasing number of links in the causal chain of given behaviors.¹⁰ These discoveries, which this Note collectively terms “the new science of human agency,”¹¹ are making it increasingly apparent that certain behaviors are the product of biological processes over which we have no control. In short, the second half of Johnson’s aphorism—that “experience [is] for” free will—is losing ground.¹²

Consider the following three findings that, by one neuroscientist’s account, evidence and exemplify a recent trend in neuroscience that will force us to “challenge our sense of self.”¹³ First, there is some evidence to suggest that those who feel they were born the wrong sex exhibit the neurophysiology of the sex with which they identify. In particular, in these individuals’ brains, a certain nucleus within the hypothalamus whose size is sex-specific is the right size according to their gender identity, but the wrong size according to their chromosomes, organs, hormones, and other phenotypical traits.¹⁴ Second,

8 See Stephen Morse, *Neuroscience and the Future of Personhood and Responsibility*, in CONSTITUTION 3.0: FREEDOM AND TECHNOLOGICAL CHANGE 113, 115, 121 (Jeffrey Rosen & Benjamin Wittes eds., 2011) (asserting that the deterministic premise that humans are “victims of neuronal circumstances” has begun to exert “a strong pull on the popular, educated imagination”).

9 See, e.g., Deborah W. Denno, *Human Biology and Criminal Responsibility: Free Will or Free Ride?*, 137 U. PA. L. REV. 615, 619-49 (1998) (summarizing research on the predictive value of genetics, hormones, neurophysiology, intellect, and sociological influences).

10 See Atiq, *supra* note 3, at 456-58 (describing a confluence of neuroscientific, genetic, and sociological research that, when combined, provide both “causal explanation and data on mechanism[s]” underlying antisocial behavior); Robert M. Sapolsky, *The Frontal Cortex and the Criminal Justice System*, 359 PHIL. TRANSACTIONS ROYAL SOC’Y LONDON 1787, 1787 (2004) (“[N]eurobiology is beginning to provide the first hints of mechanistic explanations for our personalities, propensities and passions.”); Eagleman, *supra* note 5.

11 For a full explanation of this term, see *infra* Section III.B.

12 See DAVIES, *supra* note 1, at 137-69 (arguing, with far more elegance and persuasive force than this parenthetical can hope to capture, that Johnson’s aphorism is collapsing under the weight of scientific discoveries which collectively indicate that “we are blind to the nonconscious capacities of our minds that generate in us the illusions regarding our agency”).

13 See Sapolsky, *supra* note 10, at 1787.

14 *Id.* This description summarizes a single study conducted in 2000 with findings largely limited to “male-to-female” transgender subjects. Frank M. Kruijver et al., *Male-to-Female Transsexuals Have Female Neuron Numbers in a Limbic Nucleus*, 85 J. CLINICAL ENDOCRINOLOGY & METABOLISM 2034, 2034 (2000). The truncated description of transgender individuals above is meant to parallel researchers’ description of that subgroup as those who “experience themselves as being of the opposite sex, despite having the biological characteristics of one sex.” *Id.* More recent scientific research into biological explanations

scientists can eliminate sexual promiscuity in certain mammalian species—in other words, change them from polygamous to monogamous—through gene therapy that enhances certain neurochemical reward receptors in the nucleus accumbens.¹⁵ Third, Huntington’s disease, a neurodegenerative disorder whose early symptoms can include increased aggression, hypersexuality, poor social judgment, and impulsivity, results from the mutation of one specific gene among tens of thousands.¹⁶ A common thread uniting these three examples is that each demystifies, to some degree, a particular personality trait, propensity, or behavior by elucidating one or more of its neurological and biological substrates. If the human affect is a car, the new science of human agency is a mechanic who has popped the hood to see how she runs.

Although these and similar findings fail to provide complete explanations for why different behaviors and propensities arise, the fraction of the causal matrix they do clarify has inspired some to reconsider popular notions of moral responsibility.¹⁷ That is, if human thoughts and actions are the product of uncontrolled causes that include biological and neural mechanisms, genetic predispositions, and past experiences (the basic premise of determinism),¹⁸ do we still deserve credit or blame for our actions? Attempted answers to this question vary widely, but generally fall into two categories. Those who answer “yes” call themselves “compatibilists” to reflect the idea that causally determined actions

behind gender identity continues to suggest that a detectable correlation may exist between neurological morphology and experienced gender. See Francine Russo, *Is There Something Unique About the Transgender Brain?*, SCI. AM. MIND (Jan. 1, 2016), <http://www.scientificamerican.com/article/is-there-something-unique-about-the-transgender-brain> (summarizing recent studies finding differences in the subcortical, cortical, and steroid-response features of the brain).

15 See Sapolsky, *supra* note 10, at 1788. Again, more recent studies have further suggested that differences in neurochemical signaling within the nucleus accumbens can cause intra- and interspecies variation in social behavior. See Elaine C. Keebaugh et al., *RNAi Knockdown of Oxytocin Receptor in the Nucleus Accumbens Inhibits Social Attachment and Parental Care in Monogamous Female Prairie Voles*, 10 SOC. NEUROSCIENCE 561, 566 (2015).

16 See Sapolsky, *supra* note 10, at 1787.

17 See, e.g., Paul Bloom, *Free Will Does Not Exist. So What?*, CHRON. REV. (Mar. 18, 2012), <http://chronicle.com/article/paul-bloom-free-will-does-not/131170>; Hilary Bok, *Want To Understand Free Will? Don’t Look to Neuroscience*, CHRON. REV. (Mar. 18, 2012), <http://chronicle.com/article/hilary-bok-want-to-understand/131168>; Jerry A. Coyne, *You Don’t Have Free Will*, CHRON. REV. (Mar. 18, 2012), <http://chronicle.com/article/jerry-a-coyne-you-dont-have/131165>; Michael S. Gazzaniga, *Free Will Is an Illusion, but You’re Still Responsible for Your Actions*, CHRON. REV. (Mar. 18, 2012), <http://chronicle.com/article/michael-s-gazzaniga-free/131167>.

18 See John Lawrence Hill, *Law and the Concept of the Core Self: Toward a Reconciliation of Naturalism and Humanism*, 80 MARQ. L. REV. 289, 330 (1997).

can be “free” under certain circumstances, such as when those actions result from conscious deliberation or rational thought.¹⁹ Most theorists hold this “metaphysically modest” view of free will.²⁰

So-called “incompatibilists,” by contrast, point out that preserving a distinction between willed and unwilled behavior is purely semantic if our thoughts and behaviors—even conscious and rational ones—are the inevitable result of uncontrolled causes.²¹ Thus, incompatibilists believe that free will and moral responsibility are impossible in a deterministic world.²² A third worldview, “libertarianism,” rejects determinism altogether and thus broadly preserves the possibility of free will.²³ Because libertarian theories posit that humans have a special capacity to transcend the natural world, academics largely reject libertarianism as a “metaphysically immodest conception of the human actor.”²⁴ Among laypeople, however, libertarianism has considerable traction.²⁵

The new science of human agency has sparked a closely related debate in legal academia—namely, whether a criminal justice system that justifies punishment in part on retributive grounds should change in light of empirical evidence casting doubt on the traditional notion that humans are self-causing agents.²⁶ This debate has focused on whether, as a theoretical matter,

19 See Gazzaniga, *supra* note 17.

20 Joshua Greene & Jonathan Cohen, *For the Law, Neuroscience Changes Nothing and Everything*, 359 PHIL. TRANSACTIONS ROYAL SOC’Y LONDON 1775, 1776-77 (2004) (describing “compatibilism” as the “dominant view among philosophers and legal theorists” and the official basis for “current legal doctrine”).

21 See OWEN D. JONES ET AL., *LAW AND NEUROSCIENCE* 129 (1st ed. 2014). Put differently, incompatibilists decline to characterize rationally made, thoughtful decisions as “free” because, in a deterministic world, those underlying rationalizations and thoughts were themselves the product of past causes. Under this paradigm, then, there is no aspect of a given outcome that lacks a comprehensive set of causal forces whose net effect produced the behavior in question.

22 *Id.*

23 *Id.*

24 See Atiq, *supra* note 3, at 462-63; Galen Strawson, *The Impossibility of Moral Responsibility*, 75 PHIL. STUD. 5, 18 (1994).

25 See Atiq, *supra* note 3, at 479 (“[T]he folk concept of free will seems libertarian.”); Anders Kaye, *Resurrecting the Causal Theory of the Excuses*, 83 NEB. L. REV. 1116, 1139 (2005); *cf.* Eddy Nahmias, *Folk Fears About Freedom and Responsibility: Determinism vs. Reductionism*, 6 J. COGNITION & CULTURE 215, 216 (2006) (paraphrasing experimental findings suggesting that “in certain conditions, most people express incompatibilist and libertarian intuitions”); Peggy Sasso, *Criminal Responsibility in the Age of “Mind-Reading,”* 46 AM. CRIM. L. REV. 1191, 1218 (2009) (same).

26 See generally Atiq, *supra* note 3, at 458-65 (describing the debate between reformists and their critics). Criminal punishment has four traditional justifications. In addition to retribution, these include deterrence, incapacitation, and rehabilitation. See Michele Cotton, *Back with a Vengeance: The Resilience of Retribution as an Articulated Purpose of Criminal*

foundational principles and specific doctrines of criminal law require the actors within its system to have free will.²⁷ For example, proponents of reform argue that because both the moral theories underlying the American legal system and specific rules like the voluntary act requirement, insanity defense, and other excuse defenses presuppose the existence of free will, the new science of human agency ought to drive revisions.²⁸ Critics of the reformists generally respond that free will is not foundational to criminal law and that, even if it is, the free will debate described above is far from settled.²⁹ This back-and-forth reveals that although the debate addresses important issues of fairness, egalitarian distribution of punishment, and civil liberty, it, much like the free will problem itself, is largely theoretical. Reform plainly has practical consequences, but both sides of the debate have failed to construct evidence-based arguments that their proposed course of action will in fact maximize the societal benefits of criminal law.³⁰

For example, two particularly prominent reformists, Professors Joshua Greene and Jonathan Cohen, have made the controversial “empirical prediction”³¹ that scientific advancements will gradually drive laypeople to doubt the “common sense, libertarian conception of free will and the retributivist thinking that depends on it.”³² This claim’s persuasive value, however, is dubious in light of two objections. First, Green and Cohen fail to offer any evidence—for example, from surveys or the science of human cognition—that this widespread moral evolution will in fact occur (the “substantiation objection”). Second, Green

Punishment, 37 AM. CRIM. L. REV. 1313, 1313 (2000).

27 See Atiq, *supra* note 3, at 465.

28 See *id.* at 458-59.

29 *Id.* at 463-66.

30 See *infra* Section I.B (describing reformist arguments and conservationist responses).

31 See Greene & Cohen, *supra* note 20, at 1781.

32 *Id.* at 1776, 1781 (characterizing their argument as amounting to “an empirical prediction that . . . as more and more scientific facts come in, providing increasingly vivid illustrations of what the human mind is really like, more and more people will develop moral intuitions that are at odds with our current social practices”). Ideas akin to Greene and Cohen’s have attracted considerable attention both inside and outside academia. In 2007, the John D. and Catherine T. MacArthur Foundation announced an initial investment of \$10 million to fund research on the intersection between law and neuroscience. The fund’s establishment was inspired in part by a building wave of both academic and mainstream literature, including Greene and Cohen’s work, that, according to the Foundation, has upset centuries-old notions of human nature and posed an important question: “How would the law deal with theories that suggest that people’s actions are not the direct result of prior intentions, that free-will is an illusion, that consciousness itself is a mere penumbra of the brain’s activities?” Jonathan Fanton, President, John D. & Catherine T. MacArthur Found., Announcement of Law and Neuroscience Project (Oct. 9, 2007), <https://www.macfound.org/press/speeches/announcement-law-and-neuroscience-project-jonathan-fanton-federal-court-house-new-york-ny-october-9-2007>.

and Cohen fail to offer any evidence that the moral evolution will have any particular effects that suggest reform is in order (the “practicality objection”). For that reason, their argument amounts to an armchair prediction based on intuitive assumptions instead of empirical evidence.

This Note draws from three strands of research to address each shortcoming: studies on the moral credibility of criminal law, the folk psychology of free will and moral responsibility, and the new science of human agency. By considering these bodies of research in concert and comparing them to American criminal law doctrine, this Note assesses the empirical credence of Greene and Cohen’s prediction and suggests its practical implications if true. Ultimately, this Note argues that lay perceptions of culpability will, in fact, adjust alongside the increasing degree to which natural, physiological explanations exist for given criminal behaviors. It next concludes that if the law fails to reflect these changing societal perceptions, the American justice system’s regulatory strength will gradually erode.

The first strand of research, which relates to moral credibility, addresses the practicality objection by describing the concrete effects of perceived injustice. Studies on moral credibility suggest that when moral intuitions do not align with the moral principles reflected in criminal laws, society becomes incrementally less willing to acquiesce, assist, and defer not only to those same criminal laws, but also to completely unrelated laws.³³ Thus, available evidence suggests that if Greene and Cohen’s prediction that scientific advancements will eventually undermine popular conceptions of free will is correct, the resultant clash between society’s morals and retributive aspects of criminal law will diminish the latter’s efficacy.

The second and third strands address the substantiation objection by showing that neuroscience and related fields are progressing in ways that have been shown to diminish people’s penchant for retribution. The second strand, which examines lay intuitions about free will and moral responsibility, collectively reports that although people largely believe in a robust notion of free will,³⁴ they attribute less blameworthiness to criminals whose behaviors resulted from an obvious and specific set of causal antecedents.³⁵ The clearer the causal chain, the less culpable

33 See, e.g., PAUL H. ROBINSON & JOHN M. DARLEY, JUSTICE, LIABILITY & BLAME: COMMUNITY VIEWS AND THE CRIMINAL LAW 6-7 (1995); Josh Bowers & Paul H. Robinson, *Perceptions of Fairness and Justice: The Shared Aims and Occasional Conflicts of Legitimacy and Moral Credibility*, 47 WAKE FOREST L. REV. 211, 258-62 (2012); Paul H. Robinson et al., *The Disutility of Injustice*, 85 N.Y.U. L. REV. 1940, 1995-97 (2010).

34 See sources cited *supra* note 25.

35 See ROBINSON & DARLEY, *supra* note 33, at 127-50; Sasso, *supra* note 25, at 1221; Azim F. Shariff et al., *Free Will and Punishment: A Mechanistic View of Human Nature Reduces Retribution*, 25 PSYCHOL. SCI. 1563, 1568 (2014); Azim F. Shariff & Kathleen D. Vohs, *The World Without Free Will: What Happens to a Society That Believes People Have*

an actor appears. The final strand suggests that recent studies, particularly in neuroscience, genetics, and sociology, are beginning to illuminate more and more segments of the causal matrix underlying given behaviors.³⁶ Thus, it appears that the new science of human agency will have downstream effects that ultimately support Greene and Cohen's calls for reform: an increasingly naturalistic picture of human behavior causes less retributivism; less retributivism diminishes moral credibility (assuming static criminal law doctrine);³⁷ and a widespread erosion of criminal law's moral credibility portends declining efficacy.

This Note proceeds by building this cascading chain of inferences in three Parts. Part I describes the current state of the debate on whether modern science should catalyze doctrinal changes and clarifies the discursive void this Note aims to fill. Part II responds to the practicality objection by describing how population-wide changes in conceptions of morality can incrementally weaken the effectiveness of the justice system. Part III argues that the new science of human agency presents a looming moral credibility problem for criminal law in light of likely shifts in the folk psychology of desert.

Before launching into discussion, however, I offer one last clarifying proviso critical to understanding this Note's logical structure: The argument that follows assesses the implications of human perception, not ontological reality. Put differently, all that matters for present purposes are people's views on free will and human responsibility, not whether free will and responsibility in fact exist. Accordingly, this Note neither defends determinism nor depends on it as a logical premise. Instead, this Note constructs an evidence-based objection to retributivism using available empirics that collectively reveal the striking malleability of human blame attributions, some of the particular situational forces

No Conscious Control Over Their Actions?, 6 SCI. AM. 77, 78 (2014); Vincent Yzerbyt & Anouk Rogier, *Blame It on the Group: Entitativity, Subjective Essentialism, and Social Attribution*, in THE PSYCHOLOGY OF LEGITIMACY: EMERGING PERSPECTIVES ON IDEOLOGY, JUSTICE, AND INTERGROUP RELATIONS 103, 123-24 (John T. Jost & Brenda Major eds., 2001).

³⁶ See, e.g., Atiq, *supra* note 3, at 454-57; Sapolsky, *supra* note 10, at 1794; see generally DAVID M. EAGLEMAN, *INCognito: THE SECRET LIVES OF THE BRAIN* (2011) (describing a number of unconscious and nonconscious substrates of human behavior and decisionmaking); JAMES FALLON, *THE PSYCHOPATH INSIDE: A NEUROSCIENTIST'S PERSONAL JOURNEY INTO THE DARK SIDE OF THE BRAIN* 9 (2013) ("In my mind, we are machines, albeit machines we don't understand all that well, and I have believed for decades that we have very little control over what we do and who we are. To me, nature (genetics) determines about 80 percent of our personality and behavior, and nurture (how and in what environment we are raised) only 20 percent.").

³⁷ Commentators often bemoan the seemingly glacial pace of criminal law's response to innovation—both scientific and otherwise. See, e.g., Richard Addelstein, *Victims as Cost-Bearers*, 3 BUFF. CRIM. L. REV. 131, 169 (1999); Michael Rustad, *Private Enforcement of Cybercrime on the Electronic Frontier*, 11 S.C. INTERDISC. L.J. 63, 96 (2001); *infra* note 41.

that affect our willingness to punish others, and the practical effects that rear when the law punishes people in ways we do not think it should. While some theorists have used the new science of human agency to argue that free will is an illusion and retributivism is unjust,³⁸ this Note repurposes that same science in service of a comparatively modest project: assessing both the likelihood³⁹ and implications⁴⁰ of a wide-scale recalibration of society's moral compass. Using that approach, this Note intends to accomplish something the first paragraph of this Introduction dismissed as unlikely: show that the free will debate has practical import.

I. REFORM VS. CONSERVATION: THE CURRENT STATE OF THE DISCOURSE

Although commentators and theorists often decry the legal system's incessant failure to adapt to relevant scientific developments,⁴¹ evidence-based changes do occur on occasion. Consider the example of eyewitness experts.⁴² In light of scientific evidence suggesting that eyewitness identification evidence is categorically unreliable and responsible for a significant number of wrongful convictions, many jurisdictions have begun allowing expert witnesses to help the jury properly weigh identification testimony by summarizing the helpful science in court.⁴³ In this example, the relevant science and attendant legal changes were both somewhat narrow in scope.

This Part describes a far more ambitious call for reform based on an ontological proposition synthesized from a vast array of scientific findings. A summary of these reformists' charge is as follows: Because the new science of human agency calls into question traditional conceptions of human responsibility, aspects of criminal law based on those outdated conceptions are unjustifiable.⁴⁴

Discussion in this Part proceeds by first describing aspects of the criminal law that reformists aim to change—namely, criminal law's foundational

38 *See infra* Section I.B.

39 *See infra* Part III.

40 *See infra* Part II.

41 *See, e.g.,* Viktoras Justickis, *Does the Law Use Even a Small Proportion of What Legal Psychology Has To Offer?*, in *PSYCHOLOGY AND LAW: BRIDGING THE GAP* 224, 225-27 (David Canter & Rita Zuckauskiene, eds., 2008) (asserting that "psychology rarely informs the law in practice"); Sapolsky, *supra* note 10, at 1788 ("[T]here are an ever-increasing number of realms in which the legal system has made little headway incorporating neurobiology.").

42 *See generally* Brian L. Cutler & Gary L. Wells, *Expert Testimony Regarding Eyewitness Identification*, in *PSYCHOLOGICAL SCIENCE IN THE COURTROOM: CONSENSUS AND CONTROVERSY* 100 (Jennifer L. Skeem et al. eds., 2009) (arguing for the use of expert witnesses to evaluate the appropriate credibility of eyewitnesses' testimony).

43 *Id.*

44 *See, e.g.,* Greene & Cohen, *supra* note 20, at 1776; Sapolsky, *supra* note 10, at 1788; Eagleman, *supra* note 5.

dependence on retributivism, as well as specific doctrines and defenses that in some way contemplate the offender's capacity for volition. Next, it describes the positions of reformists, who feel that current law ought to change in light of the new science of human agency, as well as responses from conservationists, who argue the opposite. This Part concludes by identifying a gap in the literature that this Note aims to fill.

A. Free Will's Place in Criminal Law

Because reformists contend that the new science of human agency calls into question common attributions of blame and moral responsibility, their proposals for reform present radical changes implicating both criminal law's foundational premises and specific criteria for criminal responsibility.⁴⁵ Although part of the debate involves different interpretations of the criminal law as written, some of the criminal law's underlying premises and specific doctrines are uncontroversial. Both sides agree that black-letter tenets of the criminal code largely do not allow defendants to use the new science of human agency to construct "volitional impairment" defenses—for example, that the criminal is not blameworthy because his criminal conduct was the product of a genetic predisposition triggered by environmental stimuli. Criminal law, as currently structured, largely precludes these sorts of defenses because it assumes human actors have some form of free will, a foundational premise that permeates specific doctrines.

Blame, responsibility, and free will play preeminent roles in the criminal justice system; these concepts are in some sense "foundational."⁴⁶ Indeed, this idea is hornbook law:

The criminal law is based on the capacity of the individual to make free choices and the assumption that virtually all of our behavior virtually all of the time is a result of free choice. This may or may not be a description of reality. But the criminal law as we know it cannot function without the hallmarks of responsibility, blame, and punishment as the working premises for most behavior.⁴⁷

Thus, instead of construing human agents in ways that are rigorously naturalistic and scientific, criminal law operates by presuming we all have some

⁴⁵ See Atiq, *supra* note 3, at 458-60.

⁴⁶ *Id.* at 458, 465; see Greene & Cohen, *supra* note 20, at 1783 (reformist); Morse, *supra* note 8, at 123-24 (conservationist); Sapolsky, *supra* note 10, at 1793 (reformist); Eagleman, *supra* note 5 (reformist).

⁴⁷ PETER W. LOW, BLACK LETTER OUTLINES: CRIMINAL LAW 199 (3d ed. 2007).

capacity for free will and moral responsibility that might justify retributive punishment.⁴⁸ Accordingly, Professor Stephen Morse characterizes criminal law's view of the human actor as "folk psychological" in that, in the law's eyes, criminal behavior must be describable using the presence or lack of colloquial, familiar mental states (for example, murderous rage or a premeditated intent to kill).⁴⁹ Although this folk psychological view of the human actor is arguably "primitive [and] pre-scientific,"⁵⁰ it has endured as a descriptive tenet of the criminal law's current organization. No matter what scientists and philosophers say about our volitional capacities, the law presumes that humans have free will in some sense of the term.⁵¹

This underlying assumption—that humans have "the general capacity for rationality" and the ability to "understand the good reasons for action and . . . conform[] to legal requirements through intentional action or forbearance"⁵²—permeates specific criminal law doctrines, including the voluntary act requirement, required culpable mental states, and defenses of excuse.⁵³ As a result, it is difficult under current doctrine to earn acquittal using a volitional impairment defense under any of those three theories.⁵⁴

Take, for example, the insanity defense, which "has traditionally been understood as vindicating the free will assumption"⁵⁵ and rarely succeeds. The insanity defense has two variations—the cognitive dysfunction test and the control dysfunction test. Typical formulations of the cognitive dysfunction test require the defendant to show that he could not appreciate the wrongfulness of his action.⁵⁶ The control dysfunction (or "irresistible impulse") test, by contrast,

48 See Morse, *supra* note 8, at 127 ("At present, the law's official position [is that] conscious, intentional, rational and uncompelled agents may properly be held responsible . . ."); see also *State Farm Fire & Cas. Co. v. Brown*, 905 P.2d 527, 535 (Ariz. Ct. App. 1995) ("The legal model's postulate of free will envisions people as morally and legally answerable for their conduct rather than as pigeons in a Skinner box. By contrast, the scientific model in most schools of psychology is largely deterministic . . .").

49 See Morse, *supra* note 8, at 127.

50 *Id.* at 124.

51 *Id.* Note the significance of the phrase "in some sense of the term." Reformists argue that criminal liability depends on a libertarian notion of free will, which involves a metaphysically robust moment of agency in which the agent transcends the laws of nature as a true first causer. Conservationists, by contrast, argue that criminal law only requires a compatibilist ontology in which "free" acts are those that are the product of conscious, rational deliberation.

52 *Id.* at 125.

53 See Atiq, *supra* note 3, at 459-60; Morse, *supra* note 8, at 124-25.

54 See Atiq, *supra* note 3, at 457-58.

55 Michele Cotton, *A Foolish Consistency: Keeping Determinism out of the Criminal Law*, 15 B.U. PUB. INT. L.J. 1, 5 (2005).

56 See ROBINSON & DARLEY, *supra* note 33, at 129; see, e.g., MODEL PENAL CODE §

enables a defendant to plead insanity even if he understood the nature of his actions so long as he lacked the ability to control his conduct and his free agency was “destroyed.”⁵⁷ Jurisdictions differ on whether defendants may plead an insanity defense under one or both of these theories of insanity.⁵⁸ Since the illustrious John Hinckley trial and the resultant passage of the Federal Insanity Defense Reform Act, which aimed in part to shrink the insanity defense’s scope and availability, the number of jurisdictions that allow defendants to plead control dysfunction has shrunk to nineteen.⁵⁹ Thirty jurisdictions allow only cognitive dysfunction and two allow no insanity defense at all.⁶⁰ Further, regardless of the type of dysfunction pleaded, successful insanity defenses are quite rare; one recent study indicated that defendants plead insanity in under 1% of criminal indictments and that insanity defenses fail 71% of the time.⁶¹ Thus, American criminal codes largely reject the idea that a person whose actions were entirely the product of uncontrolled mental and sociological processes should earn acquittal by virtue of insanity, and in the minority that do, the chances of succeeding on such an argument are slim.

“Diminished capacity” defenses have proved similarly unsuccessful. Under this strategy, defendants use volitional impairment evidence to negate mens rea

4.01(1) (AM. LAW INST., Official Draft 1985) (“A person is not responsible for criminal conduct if at the time of such conduct as a result of mental disease or defect he lacks substantial capacity . . . to appreciate the criminality [wrongfulness] of his conduct . . .”); *Clark v. State*, 588 P.2d 1027, 1029 (Nev. 1979) (noting that the jury’s duty under the M’Naughten rule was to determine whether the “appellant knew the nature and quality of her acts, had the capacity to determine right from wrong or knew whether she was doing wrong when she committed the crime”).

⁵⁷ See ROBINSON & DARLEY, *supra* note 33, at 129-30; see, e.g., MODEL PENAL CODE § 4.01(1) (“A person is not responsible for criminal conduct if at the time of such conduct as a result of mental disease or defect he lacks substantial capacity . . . to conform his conduct to the requirements of the law.”); *Godley v. Commonwealth*, 343 S.E.2d 368, 370 (Va. Ct. App. 1986) (“The defense is only available where the accused’s mind has become ‘so impaired by disease that he is totally deprived of the mental power to control or restrain his act.’”) (quoting *Thompson v. Commonwealth*, 70 S.E.2d 284, 292 (Va. 1952)).

⁵⁸ See Robinson et al., *supra* note 33, at 1956.

⁵⁹ Melinda Carrido, Note, *Revisiting the Insanity Defense: A Case for Resurrecting the Volitional Prong of the Insanity Defense in Light of Neuroscientific Advances*, 41 SW. U. L. REV. 309, 311, 319-22 (2012) (discussing the Insanity Reform Defense Act, Pub. L. No. 98-473, § 402(a), 98 Stat. 2057, 2057 (1984) (codified as amended at 18 U.S.C. § 17(a) (2012))). Passage of the Insanity Defense Reform Act reflected, to some degree, Congress’s response to the national furor that accompanied Hinckley’s acquittal. See *United States v. West*, 962 F.2d 1243, 1249 (7th Cir. 1992); *United States v. Cameron*, 907 F.2d 1051, 1061 (11th Cir. 1990).

⁶⁰ Robinson et al., *supra* note 33, at 1955-56. These numbers are accurate as of 2010.

⁶¹ Cotton, *supra* note 55, at 18 & n.90.

elements.⁶² As a practical matter, Federal Rule of Evidence 704(b) and state law equivalents limit this approach by preventing experts from testifying that a particular mental disease or defect negated a defendant's culpable mental state.⁶³ Thus, rules like 704(b) preclude experts from entering into evidence the deterministic hypothesis that, although a given defendant's actions meet the relevant actus reus elements, he lacked the requisite mental state—purpose, knowledge, recklessness, or negligence⁶⁴—because his conduct was instead the product of subconscious, nonconscious, or otherwise uncontrolled causes. Note that this hypothesis is contrary to the folk psychological conception of human acts, which posits that all behavior is “at least rationalizable by mental-state explanations.”⁶⁵

The few innovative defense lawyers that have sidestepped 704(b) and attempted this strategy have found mixed success.⁶⁶ For example, in a 2007 sexual abuse case, the defendant admitted evidence that frontal lobe defects rendered him physiologically unable to form the sort of intent or plan required under the relevant statute.⁶⁷ That defendant was convicted and received a sentence of eighteen years to life.⁶⁸ In the notorious “twinkie defense” case, by contrast, a defendant successfully avoided a first degree murder conviction by arguing that a combination of junk food and extreme stress altered his mental state at the time of the killings.⁶⁹ Although these sorts of biological deficiency cases are highly publicized, they are quite risky and exceedingly rare.⁷⁰

As currently structured, the American criminal justice system offers defendants limited means to avoid or diminish criminal liability through evidence that their criminal behavior was causally determined by biological,

62 See *id.* at 18-23; see also Deborah W. Denno, *Crime and Consciousness: Science and Involuntary Acts*, 87 MINN. L. REV. 269, 285 (2002) (“Diminished capacity can either be a complete defense resulting in an acquittal, like automatism/unconsciousness, or, more commonly, a partial defense resulting in the defendant’s conviction of a lesser crime.”).

63 See FED. R. EVID. 704(b); Cotton, *supra* note 55, at 19-20 & n.95 (listing similar state rules).

64 These four culpable mental states were drawn from the Model Penal Code provision that details general culpability requirements. See MODEL PENAL CODE § 2.02(2) (AM. LAW INST., Official Draft 1985).

65 Morse, *supra* note 8, at 123.

66 See Denno, *supra* note 9, at 616 (noting a series of innovative defenses in recent, high-profile criminal cases).

67 See Atiq, *supra* note 3, at 457.

68 *Id.* at 458.

69 Denno, *supra* note 9, at 616-17 (referring to Dan White’s diminished-responsibility defense to first-degree murder charges for the killing of Mayor George Moscone and Supervisor Harvey Milk).

70 *Id.* at 616 (“Judges and juries have not accepted most of the ‘new’ and highly publicized criminal law defenses.”).

neurophysiological, psychological, and environmental causes. To wit, neither the insanity defense nor the diminished capacity defenses offer defendants reliable means to achieve those ends. This should come as no surprise given that, as the Supreme Court has noted, “a deterministic view of human conduct . . . is inconsistent with the underlying precepts of our criminal justice system.”⁷¹

One set of these “underlying precepts” that determinism does not offend, however, is our criminal justice system’s triad of utilitarian goals: deterring future crime (deterrence), eradicating recidivism (rehabilitation), and removing irreversibly dangerous criminals from society (incapacitation).⁷² Unlike our system’s fourth traditional goal—retribution—utilitarian goals aim only to achieve practical benefits for society without labeling criminal misconduct as morally right or wrong.⁷³ For that reason, a hypothetical system founded only on utilitarian ideals would not crumble upon the wholesale rejection of free will and responsibility as accurate models of human behavior. In that system, each blameless violator would receive punishments on the sole rationale that those punishments affect behavior in ways that benefit society. Thus, although certain aspects of the American criminal justice system currently depend on the concepts of free will and responsibility, not all do. The question thus becomes: Given that modern science is gradually lending stronger and stronger empirical credence to a deterministic model of the human actor, should those aspects of our system dependent upon concepts of free will and responsibility adapt?

B. The Debate: Reformist Arguments and Conservationist Responses

The charge for reform reduces to two principal arguments, one normative and the other predictive: first, that current legal doctrine is unjustifiable insofar as it assumes a libertarian notion of free will that contemporary science overwhelmingly rejects;⁷⁴ and second, that the criminal justice system reflects societal intuitions of justice, which will soon evolve towards a deterministic worldview in light of compelling scientific discoveries.⁷⁵ These two arguments are related; in theory, as contemporary science convinces more and more people of the normative proposition, the criminal law will adapt as suggested in the predictive one.

⁷¹ *United States v. Grayson*, 438 U.S. 41, 52 (1978). This conjecture is either poorly worded or evidence that the *Grayson* majority are incompatibilists. As noted above, compatibilists believe that free will and blameworthiness are intelligible concepts in a deterministic world.

⁷² Cotton, *supra* note 26, at 1316-17.

⁷³ *Id.*

⁷⁴ See, e.g., Sapolsky, *supra* note 10, at 1794; Eagleman, *supra* note 5.

⁷⁵ See generally Greene & Cohen, *supra* note 20, at 1776 (asserting that the findings of modern science will cause widespread “rejection of free will”).

Reformists' first argument reflects the general idea that because criminal law's bedrock principles of blame and responsibility are outdated, the law itself is unfair, inhumane, and needlessly inconsistent with scientific reality.⁷⁶ Neuroscientists David Eagleman and Robert Sapolsky each relay this view in articles similar in structure. Both describe especially vivid neurological mechanisms known to affect behavior before explaining why, in light of that science, the natural world is best described as deterministic and incompatible with moral responsibility.⁷⁷ Eagleman, for example, reviews the science of genetics, unconscious cognitive processes, and environmental influences before arguing that a "modern understanding of the brain" requires "[b]lameworthiness [to] be removed from the legal argot."⁷⁸ Instead of justifying punishment on the basis of retribution or desert, Eagleman argues, punishments should focus exclusively on the consequentialist, utilitarian goals of deterrence, rehabilitation, and incapacitation.⁷⁹

Sapolsky's position is similarly incompatibilistic. He asserts that, given the growing body of research providing "mechanistic explanations for our personalities, propensities, and passions," including evidence that a malfunctioning prefrontal cortex renders some individuals biologically incapable of making "good" decisions instead of "bad" ones, the law's focus on blame instead of past causes is misguided.⁸⁰ Accordingly, just like Eagleman, Sapolsky recommends dispensing with retributivism, albeit in a more colorful fashion:

To understand is not to forgive or to do nothing; whereas you do not ponder whether to forgive a car that, because of problems with its brakes, has injured someone, you nevertheless protect society from it. . . . [And] although it may seem dehumanizing to medicalize people into being broken cars, it can still be vastly more humane than moralizing them into being sinners.⁸¹

Whereas the neuroscientists' argument is normative, the legal theorists' argument is perhaps best understood as predictive. Professors Joshua Greene and Jonathan Cohen advance the provocative and much-discussed⁸² view that although laypeople overwhelmingly believe themselves to have a robust power of free will, neuroscientific advancements will gradually change that intuition by revealing, with increasing clarity and vividness, that our actions are driven by

⁷⁶ See sources cited *supra* notes 71-72.

⁷⁷ *Id.*

⁷⁸ Eagleman, *supra* note 5.

⁷⁹ *Id.*

⁸⁰ Sapolsky, *supra* note 10, at 1788.

⁸¹ *Id.* at 1794.

⁸² See, e.g., Atiq, *supra* note 3, at 458.

neurological and environmental processes that we cannot control.⁸³ This moral revolution, they argue, will involve society's wholesale rejection of both free will and moral responsibility—that is, people will reject both libertarianism (robust free will) and compatibilism (“metaphysically modest”⁸⁴ free will)—and thus adopt a worldview that clashes with the law's current dependence on blame and retributivism.⁸⁵ Accordingly, because criminal law doctrines “exist because they more or less adequately capture an intuitive sense of justice,” the law will inevitably evolve by replacing retributivist justifications for punishment with utilitarian ones.⁸⁶

Critically, Greene and Cohen do not assert that criminal law “officially” depends on robust free will.⁸⁷ They admit that criminal law purports to only require a “metaphysically modest” version of free will that is compatible with both determinism and retribution.⁸⁸ But regardless of what the law “says,”⁸⁹ they argue, it *in fact* depends on the intuitions that society currently ascribes to it: libertarianism and compatibilism.⁹⁰ That is, although it is logically coherent for the law to use words like blame, responsibility, and just deserts even if the world is deterministic thanks to the philosophy of compatibilism, that is an “unstable marriage” because it is not intuitive and the law necessarily reflects societal intuitions.⁹¹ Simply put, society does not see things that way, so the law does not work that way.⁹² Instead, society intuitively believes criminal law punishes people because they deserve it, an intuition that will lead people to question criminal law once the science convinces them that determinism is true and blame is nonsensical.

Conservationists like Professor Stephen Morse respond with two principal objections: (1) neuroscience does not currently support the conclusion that we are not agents; and (2) even if it does, criminal law need not change because it embraces a form of free will that is compatible with determinism.⁹³ First, Morse argues that because the science of agency is still “in its infancy,”⁹⁴ we cannot

83 See Greene & Cohen, *supra* note 20, at 1776.

84 *Id.* (advocating instead for a consequentialist view of free will).

85 See *supra* note 20 and accompanying text.

86 Greene & Cohen, *supra* note 20, at 1776.

87 *Id.*

88 *Id.* (defining this view as “compatibilism”).

89 *Id.*

90 *Id.* (“[W]e argue that the law’s intuitive support is ultimately grounded in a metaphysically, overambitious, libertarian notion of free will that is threatened by determinism and, more pointedly, by forthcoming cognitive neuroscience.”).

91 *Id.*

92 *Id.*

93 See Morse, *supra* note 8, at 119-21.

94 *Id.* at 119.

justifiably claim that the mental states posited by the folk psychological model are “chimera[s]” that have zero explanatory power.⁹⁵ At present, neuroscience cannot yet explain “how molecules, which have no intentionality or temporal sense, produce intentional creatures with a sense of past, present and future that guide our lives.”⁹⁶ Watching neurons fire on a brain scanner is one thing; providing a complete, physicalist explanation for a mental state (for example, someone’s plan to steal a jewel) is wholly another. Because current science explains so little about these “brain-mind” and “brain-action” connections, Morse argues, reshaping our societal institutions based on it would amount to “neuroarrogance.”⁹⁷

In addition to this critique of the science, Morse emphasizes that which Greene and Cohen concede: substantive legal doctrine does not depend on robust free will.⁹⁸ That is, criminal law does not require human agents to all be transcendent self-causers in order to justifiably attribute blame. Criminal law instead operates on compatibilist premises that allow the system to attribute moral responsibility to any criminal actor with the capacity for “conscious, intentional, [and] rational” behavior.⁹⁹ We can still distinguish between the folk psychological states of conscious behavior and unconscious or uncontrolled behavior even in a deterministic world. Thus, at least in theory, criminal law need not adapt if determinism is true.

C. This Note’s Role in the Discourse

Morse’s response to Greene and Cohen’s empirical prediction is cogent but perhaps incomplete. He argues that because science might never disprove human agency, Greene and Cohen’s envisioned moral revolution will not occur.¹⁰⁰ Conservationists might object to Greene and Cohen’s prediction on two additional grounds.

First, Greene and Cohen fail to provide any evidence from the behavioral sciences that society will completely shed a popular, prevailing belief in robust free will, moral responsibility, and retributivism. In fact, the only scientific evidence they do offer is research from neuroscience and cognitive genetics

⁹⁵ *Id.* at 122.

⁹⁶ *Id.* (criticizing the post-Enlightenment “reductionist” view of free will).

⁹⁷ *Id.* Since this Note focuses on the significance of human perception instead of the ontological validity of determinism, this Note takes no position on this aspect of the debate.

⁹⁸ *Id.* at 119 (“[F]ree will plays no doctrinal role in criminal law and it is not genuinely foundational for criminal responsibility. Nor is determinism inconsistent with the folk psychological view of the person.”).

⁹⁹ *Id.* at 120.

¹⁰⁰ *Id.* at 128.

indicating that humans are hardwired to punish others.¹⁰¹ Thus, it is doubtful from their account that widespread beliefs in moral responsibility will erode even in the face of scientific advancements that support a deterministic worldview. Recall that this Note termed this apparent unlikelihood the “substantiation objection.”

Second, assuming this moral revolution does occur, its practical implications are unclear. Greene and Cohen assert that the law will simply adapt to align with prevailing societal views, but this account is opaque and largely unsupported in their article. Not only do the authors fail to specify how the law will adapt, but also why—legislators often pass laws, policies, and programs that people disagree with on some level. Greene and Cohen fail to offer practical reasons why we should completely reorganize our criminal law to accommodate people’s feelings aside from, perhaps, the ethereal promise of fairness. Recall that this Note termed this the “practicality objection.”

This Note offers responses to both objections. First, it responds to the practicality objection by pointing to research on the moral credibility of substantive criminal laws and their real-world outputs.¹⁰² Because studies on this topic indicate that perceived injustice incrementally diminishes people’s willingness to comply with the rule of law, widespread rejection of one of criminal law’s foundational tenets could weaken the law’s regulatory efficacy.

Second, this Note predicts that advancements in neuroscience and related fields may in fact present a looming moral credibility problem in light of cutting-edge research showing that people—even those who believe in robust free will—tend to view defendants as less culpable if a granular and reductionistic explanation exists for their conduct.¹⁰³ Because the new science of human agency is beginning to illuminate these compelling physical explanations, people’s moral intuitions about given defendants’ culpability may in fact change *even if their views on free will remain static*.

That is a critical distinction worth briefly highlighting. Greene and Cohen argue that the new science of human agency will cause broad-based changes in criminal law once people stop believing in free will. This Note, by contrast, argues that the new science will have the practical effect of diminishing criminal law’s efficacy in the near term even if people hold fast to libertarianism.

Finally, a quick word on this Note’s discursive potency: this Note does not purport to comprehensively argue that, as a normative matter, the criminal law should dispense with retributivism or otherwise reorganize to accommodate changing communal views. Instead, it is best construed as a single arrow in the

101 Greene & Cohen, *supra* note 20, at 1784 (suggesting that “the impulse to exact punishment may be driven by phylogenetically old mechanisms in the brain”).

102 See *infra* Part II.

103 See *infra* Part III.

reformists' quiver; an evidence-based prediction that the new science of human agency may have important, practical implications for the criminal justice system even if Greene and Cohen's prediction of a general moral revolution in criminal law proves false.

II. MORAL CREDIBILITY: THE PRACTICAL EFFECTS OF PERCEIVED INJUSTICE

Greene and Cohen's empirical prediction that community views will soon clash with criminal law's bedrock principles of blame and responsibility has a number of commonsense implications.¹⁰⁴ Greene and Cohen foresee one such effect—that changes in social morality will precipitate changes in the law—but there are surely others. For example, in theory, criminal laws that accurately reflect society's moral intuitions about justice should constitute potent deterrents for anyone who values social acceptance.¹⁰⁵ A criminal code that fails to wield the power of our natural aversion to judgment, stigmatization, and interpersonal ostracism misses out on a cost-free, powerful guarantor of compliance.¹⁰⁶ Similarly, and perhaps more obviously, people are probably more likely to comply with laws they agree with simply because they think complying is the right thing to do.¹⁰⁷ These intuitions provide the beginnings of an answer to the practicality objection, but recent empirics indicate we can do better.

A growing body of research suggests that aligning the law's various moral judgments with those of society has a number of utilitarian benefits.¹⁰⁸ Researchers generally refer to the capacity of a given law to accurately and authoritatively reflect the moral intuitions of the relevant community as the law's "moral credibility."¹⁰⁹ Studies have shown that consequences exist for drafting or maintaining laws that lack moral credibility. When people disagree with a principle of justice that a given law reflects, they are less likely to comply with that law,¹¹⁰ comply with other unrelated laws,¹¹¹ and cooperate with the criminal justice system as discretionary actors (for example, as witnesses and jurors).¹¹² Moral mismatches have also been shown to encourage deviant behavior in

104 See ROBINSON & DARLEY, *supra* note 33, at 6.

105 *See id.*

106 *See id.*

107 *See, e.g., id.*

108 Robinson et al., *supra* note 33, at 1995.

109 ROBINSON & DARLEY, *supra* note 33, at 6; Bowers & Robinson, *supra* note 33, at 240-41; *see also* Robinson et al., *supra* note 33 (using "moral credibility" and "perceived justice" interchangeably).

110 *See* ROBINSON & DARLEY, *supra* note 33, at 7.

111 *See* Bowers & Robinson, *supra* note 33, at 262.

112 *See* ROBINSON & DARLEY, *supra* note 33, at 7.

general.¹¹³ Further, the relationship between a law's moral credibility and its compliance power appears to be proportional.¹¹⁴ Thus, people do not simply indicate they will comply with laws they agree with and flout the ones they do not. Instead, the extent of subjects' past transgressions and self-reported likelihood of future transgression tracks the depth of their moral objections to the laws they oppose.¹¹⁵

Like all correlational studies, however, studies on the effects of perceived injustice have limitations that affect their generalizability. Accordingly, to determine whether changes in societal intuitions about free will and moral responsibility will trigger the practical effects observed in the research, one must examine these studies' design and methodology in search of relevant constraints.

Studies on moral credibility have employed both controlled and observational research methods.¹¹⁶ In the controlled studies, experimenters typically begin by exposing some subjects—only those in the experimental group—to a crime, law, or conviction that the subject may or may not characterize as just.¹¹⁷ Methods of exposure include mock newspaper articles, mock television news reports, or simply telling the subject about the crime or legal outcome in an interview or questionnaire.¹¹⁸ To gauge the effects of perceived injustice, experimenters either (1) observe subjects' frequency of engaging in subsequent deviant behavior like stealing a pen¹¹⁹ or committing jury nullification in a mock trial,¹²⁰ or (2) rely on subjects' self-reported future likelihood of violating the law or cooperating with the criminal justice system in other ways.¹²¹ Those other ways include reporting known crimes to authorities, turning in evidence to the police, and reporting their own accidental violations.¹²²

Observational studies, by contrast, have the benefit of examining the effects of real-life exposure to injustice. Subjects in these studies served as jurors in criminal court proceedings,¹²³ committed a crime themselves,¹²⁴ or knew a friend

¹¹³ See Robinson et al., *supra* note 33, at 2011-16.

¹¹⁴ *Id.*; see also Bowers & Robinson, *supra* note 33, at 258 (asserting that “[m]inor changes in moral credibility incrementally affect people’s willingness to acquiesce, assist, and defer to the criminal law”).

¹¹⁵ Robinson et al., *supra* note 33, at 2011.

¹¹⁶ *Id.*

¹¹⁷ *Id.*

¹¹⁸ *Id.*

¹¹⁹ *Id.* at 2015.

¹²⁰ *Id.* at 2014.

¹²¹ *Id.* at 2011-16.

¹²² Bowers & Robinson, *supra* note 33, at 258.

¹²³ *Id.* at 259.

¹²⁴ Robinson et al., *supra* note 33, at 2012.

or relative who suffered a legal outcome that the subject perceived as unjust.¹²⁵ Thus, the behavioral aftereffects observed among these subjects might more accurately reflect reactions to moral objections.

Importantly, the results of observational and experimental studies align. Both indicate that maximizing the law's moral credibility brings the utilitarian benefits of improving criminal law's potency as a deterrent and increasing the likelihood that civilian actors will contribute to the efficacy of the system as jurors, witnesses, and bystanders.¹²⁶

These findings have a number of limitations. First, the studies indicating that one law's low moral credibility subtly encourages people to flout other laws only observed or asked about future transgression of minor offenses—things like speeding, smoking marijuana, or parking illegally.¹²⁷ Thus, the extent of experimenters' observed "general deviance" effect is unknown.¹²⁸ Further, the studies' reliance on self-reporting to predict actual behavior may have been necessary for practical reasons, but is nevertheless dubious. Subjects may or may not be accurate judges of their own propensities, especially given that some may have been subconsciously primed to answer in certain ways due to the nature of preceding questions.

Finally, exposure—the method by which subjects learned that their version of justice conflicted with the law's—poses two separate limitations. First, the research does not indicate how likely it is that segments of the population who disagree with a given law will in fact confront that law. People must either experience moral mismatches directly (as a defendant or juror) or indirectly (through news reports or interpersonal contacts); low moral credibility does not per se diminish the law's efficacy. Because laypeople do not spend their Saturday mornings reading their state criminal codes, direct and indirect contact are probably the only two realistic mediums of exposure. Second, studies do not indicate how long a given person's exposure to a moral mismatch impacts their likelihood of future compliance. For all of these reasons, one must read the literature with caution.

Nevertheless, the science summarized above addresses the practicality objection by identifying certain effects that might follow shifts in society's moral landscape. To wit, the research indicates that (1) if a person observes or hears about a legal outcome she deems unjust, then (2) for an unknown period of time she will be less likely to comply, acquiesce, or cooperate with at least one

¹²⁵ *Id.* at 2015-16.

¹²⁶ ROBINSON & DARLEY, *supra* note 33, at 7.

¹²⁷ *See, e.g.,* Robinson et al., *supra* note 33, at 2011-16.

¹²⁸ *See* Marc Le Blanc & Rolf Loeber, *Developmental Criminology Updated*, 23 CRIM. & JUST. 115, 118-119 (1998) (discussing the definition and evolution of the term "general deviance" in criminology).

criminal law, procedure, or process. If Greene and Cohen's prediction is true—that society will soon adopt views on human agency that directly clash with criminal law's terms and consequences—then moral mismatches will result. Further, so long as individuals experience direct or indirect exposure to those terms and consequences, the research on moral credibility indicates that some percentage of those exposed will actually change their behavior in ways that conflict with our system's rules or impede its processes. The magnitude of this effect is currently unclear, however, because the research provides limited guidance on the extent to which populations will have direct or indirect exposure to legal outputs they disagree with, the length of time problematic behavior persists after exposure, and the number and nature of crimes that exposed individuals are likely to violate.

A conservative application of the research on moral credibility supplies a plausible reason for concern if the new science of human agency drives Greene and Cohen's predicted moral revolution and our criminal law remains unchanged. Further, because Greene and Cohen predict radical shifts in morality that could change society's holistic views of our criminal justice system, alternative applications of the science might predict more extreme effects. Thus, both conservative and aggressive extrapolations indicate that, at the very least, a gradual erosion of retributivism's moral credibility might result in practical effects worth consideration by policymakers: criminal law may begin to suffer diminishing compliance, cooperation, and efficacy.

III. A LOOMING MORAL CREDIBILITY PROBLEM

Part II assumes that Greene and Cohen's moral revolution will occur and concludes that such a radical shift would precipitate practical difficulties not mentioned in their article. This Part, by contrast, sheds that assumption and asks whether society's intuitions will in fact change in ways that matter—that is, in ways that will trigger the problems associated with low moral credibility. This Part's discussion proceeds in three Sections. First, Section III.A examines a recent strand of scientific literature that both maps folk intuitions about criminal responsibility and explains what situational factors drive those intuitions. Second, Section III.B describes the new science of human agency and assesses whether it will reinforce or shape the intuitions charted in Section III.A. Finally, Section III.C builds this Note's central thesis by synthesizing these piecewise conclusions into a single model that predicts a forthcoming moral credibility problem.

Before delving into the science, though, we must specify which folk intuitions are relevant to examine and predict. Recall that one key aspect of Greene and Cohen's predictive account is that the new science of human agency will prove that both determinism and incompatibilism (or "hard determinism")

are accurate descriptions of reality.¹²⁹ Thus, in their view, every event in the natural world—including all human thought and behavior—is wholly the product of a complex matrix of causal antecedents and that state of affairs renders the man-made concepts of free will, blame, and responsibility nonsensical.¹³⁰ In their view, you do not deserve blame for reaching into the cookie jar; you were the hapless puppet of neuronal and environmental circumstances beyond your control. They further argue that society writ large will also grow to adopt that two-pronged worldview—one that both accepts determinism and rejects free will and responsibility.¹³¹

The only communal view relevant for present purposes, however, is a communal view that could clash with the principles of morality reflected in criminal law. And because the criminal law does not reflect or depend on a deterministic worldview, folk intuitions about free will and responsibility are all that matter. Whereas a determinist-incompatibilist from Greene and Cohen's future world would disagree with criminal law's current fixation on retributivism and be offended by a defendant's inability to claim a volitional impairment defense, a determinist-compatibilist would see no problem with either. Thus, the analysis below does not ask whether the new science of human agency will produce determinists, but rather how the new science of human agency will affect intuitions about free will and responsibility.

A. Folk Intuitions: Facts and Determinants

Although some scholars argue that a modern, scientific worldview presupposes determinism as an accurate description of reality,¹³² determinism is less popular among laypeople.¹³³ Most people not only understand themselves as having robust free will,¹³⁴ but also downplay the extent to which deterministic factors like biology and environmental circumstances drive behavior.¹³⁵ In one

129 See Greene & Cohen, *supra* note 20, at 1776. Note that this position leaves open the possibility of some notion of responsibility, although not the sort of responsibility one might typically imagine. On their view, a criminal in a deterministic world is responsible for his actions insofar as he can be held accountable on consequentialist grounds. *Id.* at 1783.

130 See *id.* at 1780 (developing a hypothetical "Mr. Puppet" to examine the fallacy of human free will).

131 *Id.* at 1776.

132 See Hill, *supra* note 18, at 291, 330; Shariff et al., *supra* note 35, at 1563 ("Although few people deny that humans regularly make uncoerced choices and exercise self-control, many scientists and philosophers have taken issue with the idea that conscious humans can generate spontaneous choices and actions not fully determined by prior events.") (citation omitted).

133 See sources cited *supra* note 25 and accompanying text.

134 See Atiq, *supra* note 3, at 478; Shariff et al., *supra* note 35, at 1563.

135 See Atiq, *supra* note 3, at 486-87.

study, for example, participants were asked to indicate what percentage of a given criminal act stemmed from free will as opposed to hard social conditions.¹³⁶ On average, respondents attributed seventy-six percent of the conduct to free will and almost one third said the act was completely (100 percent) willed.¹³⁷ Further, societal beliefs in free will are similarly sturdy. Another study found that subjects clung to a belief in free will and moral responsibility even when asked to assume the truth of determinism.¹³⁸ Thus, for most people, free will is both real and possible in a deterministic world.¹³⁹

In one sense, free will's durability and widespread appeal is not surprising. Johnson's aphorism rings true in that our everyday experiences seem to constantly confirm free will's presence. For example, the act of wagging a finger after commanding oneself to do so produces a powerful emotion of authorship. Intuitive appeal aside, there may be a better explanation for free will's popularity—namely, empirical evidence indicating that a belief in free will may itself be the product of entrenched cognitive processes operating beneath the level of conscious awareness.¹⁴⁰ Theorists have pointed to a number of different systemic features of our psychology in support of this idea,¹⁴¹ among them the so-called fundamental attribution error. This error describes people's tendency to explain human behavior in dispositional rather than situational terms.¹⁴² Because research shows that "individuals are especially prone to underemphasize the role of situational factors in the context of crime and punishment,"¹⁴³ one practical upshot might be that folk explanations for behavior prevail over scientific ones both in the jury room and as a general matter. Because reviewing the remainder of theories supporting the idea that free will and moral responsibility are to some degree structurally entrenched within our psyche would take more space than this Note can spare, suffice it to say that the idea is controversial, yet plausible.

Free will's deep-rooted appeal seems to spell trouble for Greene and Cohen, since beliefs in free will predict stronger tendencies toward retributivism.¹⁴⁴ If

¹³⁶ *Id.* at 487.

¹³⁷ *Id.*

¹³⁸ Nahmias, *supra* note 25, at 215.

¹³⁹ *See id.* at 215-16.

¹⁴⁰ *See* Davies, *supra* note 11, at 166-69. The supreme irony of this conjecture is not lost on the author.

¹⁴¹ *See id.* (discussing the dual affect the theories of naïve realism and apparent mental causation have on human perception of authorship). *See generally* DANIEL M. WEGNER, *THE ILLUSION OF CONSCIOUS WILL* (2002) (constructing the theory of apparent mental causation, which generally posits that the experience of conscious will results from a cognitive system that both produces an emotion of authorship and reinforces that emotion by producing subsequent, conflated causal explanations for the conduct in question).

¹⁴² *See* Atiq, *supra* note 3, at 476-77.

¹⁴³ *Id.* at 476.

¹⁴⁴ Shariff & Vohs, *supra* note 35, at 78.

systemic cognitive mechanisms motivate us to preserve our beliefs in free will and responsibility, then our intuitions may in fact never collide with the compatibilist policies currently reflected in criminal law. Despite advancements in science, people might nonetheless continue to see criminals as morally responsible because our concepts of free will and blame are both intuitive and, as Greene and Cohen admit, entrenched in our psychology.¹⁴⁵

Research on the popularity of libertarianism and the psychology of mental causation,¹⁴⁶ however, only tells half of the story. The remainder of research mapping out communal intuitions shows that, despite an enduring belief in free will, people exhibit a tendency to absolve criminals of blame if the biological and situational antecedents of the criminal's behavior are vivid enough.¹⁴⁷ This tendency is both consistent with the research already discussed in this Part and supported by additional evidence. The research above indicates that people do not instantly revert to incompatibilism when forced to contemplate a deterministic universe; they preserve a faith in free will and responsibility. The set of studies described below shows that, as people learn about greater and greater portions of the causal matrix underlying different thoughts and behaviors, they become incrementally less likely to apportion blame regardless of their beliefs in free will.

Findings drawn from one of the first¹⁴⁸ large-scale attempts to measure society's moral intuitions support the related premise that attributions of blame diminish stepwise alongside the degree of perceived control the criminal actor has. Professors Paul Robinson and John Darley uncovered this pattern while performing research explicitly designed to compare communal views with the letter of the law.¹⁴⁹ Their research design was simple. Subjects read a series of scenarios depicting various crimes being committed and assigned a liability score to the criminal in each scenario.¹⁵⁰ The liability scores subjects gave imaginary defendants in classic excuse defense scenarios—including insanity, involuntary intoxication, and duress—are particularly illustrative of the sliding scale of liability and control described above.

145 Greene & Cohen, *supra* note 20, at 1782 (reporting research showing that “humans have a set of cognitive subsystems that are specialized for processing information about intentional agents”).

146 The term “mental causation” refers, as a general matter, to the mind's tendency to drive the subjective experience of willed agency even if that conclusion departs from reality. See sources cited *supra* note 141.

147 See ROBINSON & DARLEY, *supra* note 33, at 127-50; Nahmias, *supra* note 25, at 230-31; Shariff et al., *supra* note 35, at 1568; Shariff & Vohs, *supra* note 35, at 78.

148 ROBINSON & DARLEY, *supra* note 33, at 2-3 (asserting that, as of 1995, neither social scientists nor psychologists had “mapped the contours of the moral intuitions of our culture”).

149 *Id.* at 3, 130-50.

150 *Id.* at 7.

To test whether society's intuitions validate or call into question the many different forms of the insanity defense, Robinson and Darley devised seven scenarios in which an imaginary culprit exhibited varying degrees of cognitive deficiency (inability to know right from wrong) and control deficiency (inability to avoid committing the crime).¹⁵¹ Results indicated that although both forms of deficiency justified lower liability scores, control dysfunction elicited a more powerful mitigation effect.¹⁵² Further, the greater the degree of control dysfunction, the lower the liability scores.

Subjects produced similar scores in the context of both involuntary intoxication and duress. Researchers devised involuntary intoxication scenarios that also varied by degree of control and cognitive dysfunction because, for most states, elements of the involuntary intoxication defense mimic those of the insanity defense.¹⁵³ Although subjects thought that involuntarily intoxicated defendants were more blameworthy than insane defendants, high levels of dysfunction predicted proportionally low liability scores in both cases.¹⁵⁴ The duress scenarios depicted defendants acting under varying degrees of coercion (from no coercion to a threat to murder the defendant's entire family) instead of dysfunction, but, predictably, also elicited liability scores arranged on a continuum that depended on the defendant's level of control.¹⁵⁵

In addition to showing that society sees degrees of liability instead of criminal law's absolutes of guilty and not guilty, Robinson and Darley's findings provided the first hints that society equates past causes with exonerating excuses. Each cause, no matter its type—biological, biochemical, situational, or otherwise—mitigated subjects' blame attributions to a degree commensurate with the cause's potency.

Recent studies have added a finer point to this sliding scale model.¹⁵⁶ They reveal that learning about the low-level causal mechanisms underlying human behavior—both with respect to a token actor's conduct¹⁵⁷ or generally applicable to all behaviors¹⁵⁸—reduces retributivism. Importantly, this correlation holds regardless of the subjects' beliefs in free will.¹⁵⁹ Thus, knowledge of or exposure to deterministic explanations of behavior appears to independently reduce people's willingness to dole out just deserts.

151 *Id.* at 130-33; *see also id.* app. A at 262-65 (providing the full text of the scenarios).

152 *Id.* at 134.

153 *Id.* at 139-40.

154 *Id.* at 155.

155 *Id.* at 147-50.

156 *See Shariff et al., supra* note 35.

157 *See Nahmias, supra* note 25, at 230.

158 *See Shariff et al., supra* note 35, at 1568; Shariff & Vohs, *supra* note 35, at 78.

159 Nahmias, *supra* note 25, at 230.

A study conducted in 2006 revealed that simply exposing people to deterministic explanations for behavior does not impact their moral intuitions.¹⁶⁰ Instead, what matters is explaining those behaviors using precise, reductionistic terms.¹⁶¹ Subjects were given two descriptions of a deterministic world and asked whether actors in each world deserved blame for their actions. However, descriptions of each world differed as follows: human behaviors in the reductionistic world were described as “*completely caused by the particular chemical reactions and neurological processes occurring in their brain*,”¹⁶² whereas human behaviors in the nonreductionistic world were described as “*completely caused by the particular thoughts, desires, and plans they have*.”¹⁶³ Responses diverged widely. Of those given the reductionistic description, only eighteen percent and nineteen percent indicated free will and moral responsibility were possible, respectively.¹⁶⁴ Those given the nonreductionistic description, by contrast, exhibited much greater ontological optimism—seventy-two percent allowed for free will and seventy-seven percent for moral responsibility.¹⁶⁵

One interpretation of these results is that libertarian intuitions remain strong in the face of determinism unless the deterministic picture relayed is causally comprehensive or otherwise vivid. Thus, its results are consistent with those of Robinson and Darley because both suggest that, as science crowds folk psychological explanations of behavior out of a causal chain, people become gradually less retributive. This study suffers from major limitations, however, including a small, nondiverse sample size (forty-nine college students),¹⁶⁶ short and simple explanations of both the reductionistic and nonreductionistic worlds, and an experimental design that in no way resembles real-world blame attributions.

A set of studies published in 2014 addressed each of these methodological flaws and reached similar results.¹⁶⁷ Researchers first exposed subjects to deterministic concepts through one of three means: a scholarly article arguing against free will; a popular science magazine article describing mechanistic neural processes but not mentioning free will; and a semester-long introductory neuroscience course.¹⁶⁸ After exposure, subjects answered a questionnaire about a fictional murderer designed to measure their desire for retributive punishment.¹⁶⁹

¹⁶⁰ *Id.*

¹⁶¹ *See id.*

¹⁶² *Id.* at 230-31 (emphasis in original).

¹⁶³ *Id.* at 231 (emphasis in original).

¹⁶⁴ *Id.*

¹⁶⁵ *Id.* at 231, 233.

¹⁶⁶ *Id.* at 230 n.16.

¹⁶⁷ *See* Shariff et al., *supra* note 35, at 1564.

¹⁶⁸ *Id.* at 1565-68.

¹⁶⁹ *Id.* at 1565-66.

Each experiment rendered the same result: exposure to sophisticated, fine-grained explanations of the neural substrates underlying human behavior reduced retributivism.¹⁷⁰

Two important limitations of the 2014 studies bear mentioning. First, they do not indicate how long the effects of exposure to deterministic explanations lasts. A reduction in retributivism that lasts only the few hours during which the vivid science is top-of-mind has little to no practical import for present purposes. In order to meaningfully impact moral credibility, a given individual's shift in moral values must last until exposure to the relevant criminal law. Second, the various methods of exposure to the science were atypical. Not many people take neuroscience courses, read science magazines, or read groundbreaking scholarly theses. The more likely method of exposure—a popular news article—may fail to provide the same level of granularity. The 2006 study addresses this limitation to some degree, however, because it changed subjects' intuitions despite only describing a marginally complex description of reality.¹⁷¹

Empirical indicators of society's moral propensities are new, but nonetheless reveal a number of patterns relevant to determining whether the new science of human agency will change society's views in ways that undermine retributivism's moral credibility. First, although widespread beliefs in free will are sturdy, people's views on moral responsibility appear to readily change upon exposure to scientific explanations for behavior that crowd out the possibility of human agency. Second, there is some evidence to suggest that this dynamic operates on a sliding scale: the clearer the scientific explanation, the greater the effect on subjective blame attributions. Finally, despite the limitation noted above, the functional triggers of these moral shifts can be commonplace—reading a magazine will do the trick. Thus, the science reasonably suggests that when the following three criteria obtain, a given actor's tendency for retributivism will diminish: (1) exposure (2) to a reductionistic, granular explanation of human behavior (3) that crowds out any explanations based on folk psychological mental states.¹⁷²

Here, the term “folk psychological mental states” refers to colloquial concepts used to describe behavior that are readily definable and coherent in everyday discourse, but opaque in strictly scientific and materialistic terms. For example, explaining that a burglary happened because the thief “was an unscrupulous guy who wanted to get rich” is a folk psychological explanation.

¹⁷⁰ *Id.* at 1568.

¹⁷¹ See Nahmias, *supra* note 25, at 230-31 (describing two relatively simple conceptions of free will that were presented to research subjects).

¹⁷² Eddy Nahmias describes “folk psychology” as “inherently non-reductionistic, explicitly requiring a role for conscious beliefs, desires, reasons, plans, and deliberations to cause our choices and actions.” *Id.* at 229.

Unlike reductionistic explanations, folk psychological ones invite blame because they seem to presuppose libertarian free will. The research supports this intuition; if people contemplate a deterministic universe described using folk psychological mental states instead of scientific, reductionistic terms, those people are more likely to preserve free will and moral responsibility.

The science reviewed in this Section is by no means a comprehensive review of the evidence relevant to addressing the substantiation objection. The volume and breadth of evidence and causal interactions one would need to examine to confirm or deny Greene and Cohen's prediction on empirical grounds would be breathtakingly vast. Nonetheless, the modest body of work reviewed in this Section suggests that, at this juncture, the idea that advancements in neuroscience and related fields can change society's moral intuitions regardless of whether it changes their views on free will is at least plausible. The next Section briefly scans the new science of human agency to evaluate the likely extent of that shift.

B. The New Science of Human Agency

In the Introduction, this Note defined the new science of agency as an emerging class of empirical literature characterized by a tendency to identify the specific neurological, genealogical, and endocrinal processes that underlie given behaviors and instances of conscious decisionmaking. Research on the causes and effects of moral evolutions, however, indicate that these new sciences have practical import beyond merely describing the natural world. To wit, the vivid causal pictures they paint may change traditional communal views on blame and responsibility in ways that may diminish retributive justice's moral credibility. This Section aims to identify the characteristics of the new science of human agency that make it especially likely to contribute a shift in our moral topography. It accomplishes that task by contrasting prior scientific attempts to explain behavior with more recent attempts.

Recall the criteria identified in Section III.A that predict a given actor's diminished sense of retributivism: (1) exposure (2) to a reductionistic, granular explanation of human behavior (3) that crowds out any explanations based on folk psychological mental states. Older studies positing deterministic explanations for human behavior generally flunk criteria (2) and (3) for a number of reasons.

First, they were largely correlational and failed to explain the low-level causal mechanisms that precipitated higher-order criminal behaviors.¹⁷³ For example, studies conducted before 1988 reported correlations between chromosomal abnormalities and increased aggression,¹⁷⁴ irregular

¹⁷³ See Denno, *supra* note 9, at 619-40.

¹⁷⁴ *Id.* at 620.

electroencephalograph readings and murderous tendencies,¹⁷⁵ and testosterone production and irritability,¹⁷⁶ but failed to explain the processes driving those correlations.¹⁷⁷ Thus, although these pre-1988 studies explained criminal behavior using the same sort of genealogical, neurological, and endocrinal evidence as the new sciences, their lack of specificity preserved large gaps in causal stories that laypeople could have filled with folk psychology.

Second, pre-1988 studies in fact invited folk psychological conjectures by relying on mental states, not physical mechanisms, as descriptive terms.¹⁷⁸ Studies reported genetic, hormonal, and cognitive abnormalities as predictive of “exaggerated maleness,”¹⁷⁹ “aggression,”¹⁸⁰ and “lack of discipline.”¹⁸¹ By using descriptors that are, to some degree, nonspecific and hard to pin down in materialistic terms, early empirics gave lay observers room to infer some degree of control on behalf of the criminal actor.

Finally, these correlational studies were widely prone to conflicting results.¹⁸² If the scientific community was not convinced of the proposed causal mechanisms’ explanatory potency, how could the public?

Next-generation research, by contrast, supplants correlational data with causal theories that delve deeply into the relevant physiological substrates of behavior.¹⁸³ Instead of descriptive terms that evoke mental causation, the new sciences refer to brain states using mechanistic terms like “diminished capacity”¹⁸⁴ and “organic impairment.”¹⁸⁵ The human agent is thus better understood under these postulates as a biological machine instead of a thinking, planning actor. Further, because this deterministic conception of the human self “exerts a strong pull on the popular, educated imagination,”¹⁸⁶ mainstream media

175 *Id.* at 637-38.

176 *Id.* at 628.

177 See sources cited *supra* notes 174-176.

178 See, e.g., Denno, *supra* note 9, at 620, 640.

179 *Id.* at 620.

180 *Id.* at 626.

181 *Id.* at 644.

182 *Id.* at 627-31, 634-36, 640, 646-48.

183 See, e.g., Atiq, *supra* note 3, at 456-57; Daniel A. Martell, *Causal Relation Between Brain Damage and Homicide: The Prosecution*, 1 SEMINARS CLINICAL NEUROPSYCHIATRY 184 (1996) (hypothesizing that physiological abnormalities in a particular defendant’s frontal lobe affected his volitional capacities); Peggy Sasso, *Implementing the Death Penalty: The Moral Implications of Recent Advances in Neuropsychology*, 29 CARDOZO L. REV. 765, 790-91 (2007) (discussing the behavioral effects of damage to the orbitofrontal cortex); Eagleman, *supra* note 5 (summarizing a body of research that, according to Eagleman, “demonstrates the limits of the [free choice] assumption”).

184 Sasso, *supra* note 183, at 790.

185 Sapolsky, *supra* note 10, at 1794.

186 Morse, *supra* note 8, at 127.

outlets have disseminated stories that implicitly or explicitly endorse deterministic sciences at a relatively high clip.¹⁸⁷ For all of these reasons, the new science of human agency meets each of the three criteria of an intuition-mover outlined above.

Two examples best illustrate this new breed of research. Consider first the example of the gene for monoamine oxidase A (MAOA).¹⁸⁸ Statistical data evidences a robust correlation between the presence of a lower-activity MAOA variant and criminally deviant behavior, but scientists have only recently discovered why.¹⁸⁹ If an MAOA carrier experiences certain environmental stimuli, this MAOA variant triggers a neurochemical response system that leads to a “functional difference” in his brain regions responsible for “anger production and control.”¹⁹⁰ Note the temporal cohesiveness of this causal picture; it describes the mechanisms responsible for the potentiality, genesis, and actualization of antisocial behavior. Although presence of the MAOA variant is by no means an independent predictor of criminality, this theory provides the sort of vivid causal story that may diminish subjective attributions of blame towards carriers of the lower-activity MAOA variant.

A second and perhaps more powerful example of the new science of human agency is Sapolsky’s account of prefrontal cortex (PFC) damage. The PFC has a number of important functions, but most relevant for present purposes is its job of “biasing an individual towards doing the ‘harder’ but ‘more correct’ behavior” instead of impulsively succumbing to the choice that provides instant gratification.¹⁹¹ Unfortunately for us, the PFC is prone to underdeveloping, sustaining damage, or otherwise misfiring for any number of reasons—namely, age, transient states of intoxication, blunt trauma, lesion, tumor, and neuronal

187 See, e.g., sources cited *supra* note 5. Perhaps the most notable example of this sort of widespread media coverage has been the story of Jim Fallon, a neuroscientist who accidentally realized his brain shared the same physiological characteristics as murderous psychopaths. Since his discovery, Fallon has featured in news stories, spoke in two TED talks, and wrote a *New York Times* bestselling book called *The Psychopath Inside*. Fallon, *supra* note 36; Susan Donaldson James, *Scientist Related to Killers Learns He Has a Psychopath’s Brain*, ABC NEWS (Nov. 30, 2013), <http://abcnews.go.com/Health/scientist-related-killers-learns-psychopaths-brain/story?id=21029246>; Fallon, *supra* note 6.

188 Atiq, *supra* note 3, at 456.

189 *Id.* at 456-57; Matthew L. Baum, *The Monoamine Oxidase A (MAOA) Genetic Predisposition to Impulsive Violence: Is It Relevant to Criminal Trials?*, 6 *NEUROETHICS* 287, 288 (2013) (“[C]arrying the low activity MAOA gene (MAOA-L) could make the subject more prone to express aggression if provoked or socially excluded.”). An Italian appeals court in 2009 reduced a defendant’s sentence for murder based on evidence that he carried this genetic variant. *Id.* at 287.

190 *Id.* at 456 (naming “childhood maltreatment” as an example of an environmental stimulus).

191 Sapolsky, *supra* note 10, at 1793.

death.¹⁹² When this happens, concomitant behavioral changes are remarkable. Studies have shown that, when presented with two options, subjects with damaged PFCs can verbalize an intent to choose the “right” option but then prove literally unable to avoid choosing the wrong one.¹⁹³ Further, this effect is proportional.¹⁹⁴ Thus, the net functional capacity of any person’s PFC, measurable by metabolic rate, depicts that person’s capacity to regulate impulsivity.¹⁹⁵ To summarize: your PFC is one yardstick (surely of many) of your volitional capacities.

Admittedly, research on the MAOA variant and PFC damage were chosen because they are especially compelling illustrations of how advancements in neuroscience and related fields are challenging traditional concepts of the human self. But that is precisely the point. Studies like these leave little space for folk psychology to infiltrate the causal matrix that governs behavior; in essence, they make determinism somewhat intuitive. For that reason, it is plausible to conclude that, in light of the three criteria above, these and related discoveries will begin to change our moral intuitions if widely disseminated. This is especially true given that, by all accounts, even Stephen Morse’s,¹⁹⁶ scientific advancements in these fields are occurring at a blistering pace.¹⁹⁷

C. Bringing It All Together: Two Dimmers and a Flip Switch

This Part has sought to contribute to the debate on whether scientific advancements justify reforming criminal law by answering a core empirical question: whether the new science of human agency will change society’s views on free will and responsibility, and if so, in what ways? Answering this question accomplishes at least two things: it both addresses the substantiation objection and illuminates another argument that reformists might make—that the new science of human agency will have the practical effect of eroding retributivism’s moral credibility.

The research reviewed in Sections III.A and III.B indicates that exposure to the new science of human agency can change individuals’ views on responsibility, but not necessarily free will. While beliefs in free will appear to remain sturdy in the face of deterministic explanations for human behavior, those same granular explanations diminish individuals’ willingness to apportion blame

¹⁹² *Id.*

¹⁹³ *Id.*

¹⁹⁴ *Id.*

¹⁹⁵ *Id.* at 1793-94.

¹⁹⁶ See Morse, *supra* note 8, at 123 (indicating that neuroscientific evidence may soon develop to the point at which it is regularly admitted in trial proceedings).

¹⁹⁷ See Hill, *supra* note 18, at 291; Justickis, *supra* note 41, at 233 (referring to psychological advancements); Shariff & Vohs, *supra* note 32, at 78.

for given criminal acts. Unlike beliefs in free will, blame attributions are fluid and responsive to the presence or absence of ascertainable causal antecedents that crowd out folk psychological explanations for behavior. Further, retributivism appears to diminish stepwise as the perceived causal power of scientific explanations increases. The new science of human agency is in the business of illuminating a growing spectrum of unconscious and uncontrolled determinants of human behavior. It is therefore plausible to conclude not only that individuals' propensities to punish retributively will decrease upon sufficient exposure to the relevant science, but also that this effect will intensify over time.

These empirical findings lend little support to Greene and Cohen's prediction that the new science will precipitate a widespread rejection of free will, moral responsibility, and aspects of our criminal justice system that seem to depend on those two concepts.¹⁹⁸ Instead, the science reviewed by this Note supports the comparatively modest empirical premise that exposure to deterministic explanations of human behavior makes people view particular criminals as somewhat less responsible for token crimes. Thus, although intuitions might shift, this Note found no empirical evidence that those intuitions will shift in the ways Greene and Cohen predict. Most people believe that free will and blame apply to causally determined behaviors, albeit to varying degrees. Whether they know it or not, most laypeople are compatibilists.

Although the body of research reviewed above does not alleviate the substantiation objection, it does present a new argument for reformists—namely, that changes to the criminal law may be necessary to avoid a moral credibility problem. Recall from Part II that some evidence indicates criminal law suffers from diminished efficacy when it produces practical outcomes that people deem unjust. If, in the context of specific criminal cases, reductionistic explanations for the deviant behavior exist but nonetheless fail to ensure acquittal or lesser sentences, moral mismatches might occur once people experience direct or indirect exposure.

To clarify this argument, consider the fact that the empirical strands summarized in Parts II and III feature proportional continua: (1) the criminal law's efficacy diminishes gradually alongside the widening gap between people's moral intuitions and legal policies; and (2) defendants are seen as proportionally less culpable as the physiological correlates of their behavior come clearer into the fore. These can be seen as dimmer switches. The criminal law, however, is better understood as a flip switch that primarily deals in bimodal absolutes—guilty and not guilty.

Although sentencing guidelines enable judges and juries to apportion punishment based on a given allowable range, criminal law is nonetheless not as

198 See Greene & Cohen, *supra* note 20, at 1776.

flexible as our two dimmer switches for two reasons. First, exposure vehicles—namely television and newspaper stories—might focus primarily on the presence or absence of conviction and gloss over the significance of the sentence handed down. In this scenario, those exposed to the broadcast would necessarily form a moral judgment based on incomplete information: a verdict and a sentence reported absent an explanation of the sentence’s severity as a relative matter. Thus, moral mismatches might form based primarily on verdicts because lay listeners, for whatever reason, fail to appreciate the significance of sentences. Second, sentencing guidelines have procedural constraints that bound the continuum. These two descriptors substantiate the intuitive premise that the law’s rule-driven processes lack the seemingly limitless malleability of individuals’ shifting conceptions of justice.

To extend the metaphor, as the new science of human agency gradually slides our retributivism dimmer switch towards “off,” the criminal law flip switch will fail to capture the same nuanced, stepwise decrease in the punishments it hands down. Resultantly, our moral credibility dimmer switch will slide towards “low” to a degree proportional to the mismatch created above. This rudimentary model illustrates the empirical reality that as the gap between retributivist tendencies and criminal law outcomes widens, moral credibility diminishes. And a broad range of recent empirics suggests that the new science of human agency is particularly likely to set this corrosive sequence in motion. Thus, unless the criminal law adapts to accommodate our developing understanding of human decision making processes, our justice system might soon face a moral credibility problem.

CONCLUSION

Retribution—the idea that we ought to punish criminals simply because they deserve it—plays a critical role in American legal discourse and policy. Indeed, the degree to which a defendant is morally culpable formally justifies, in part, imposition of the U.S. criminal justice system’s ultimate sanction: the death penalty.¹⁹⁹ This Note’s findings provide one practical reason why scientific developments should inform the manner in which we apply the concepts of responsibility and blame in given scenarios—namely, that failure to do so will diminish criminal law’s efficacy.

That is not to say, however, that our justice system has demonstrated a complete failure to adapt in light of available empirics. In *Roper v. Simmons*, for example, the U.S. Supreme Court cited research on developmental psychology to

¹⁹⁹ *Roper v. Simmons*, 543 U.S. 551, 571 (2005) (“We have held there are two distinct social purposes served by the death penalty: ‘retribution and deterrence of capital crimes by prospective offenders.’”) (quoting *Atkins v. Virginia*, 536 U.S. 304, 319 (2002)).

support its holding that executing a minor violates the Eighth Amendment's ban on cruel and unusual punishment.²⁰⁰ There, the Court reasoned that a minor's irresponsible conduct is "not as morally reprehensible as that of an adult" due to observable differences in minors' decision-making and volitional capacities.²⁰¹ To wit, "scientific and sociological studies" confirmed that youths are categorically more impulsive, susceptible to environmental pressures, and affectively malleable than adults.²⁰² In light of that available evidence, the Court explained, youths are less blameworthy and therefore undeserving of extreme retribution.²⁰³ The *Roper* Court thus explicitly attempted to accomplish that which the science reviewed in this Note recommends: reducing criminal liability to a degree commensurate with a given criminal actor's organic volitional capacities.

In addition to supporting the relatively uncontroversial idea that the law should periodically adapt in light of changing scientific realities, this Note's findings inform a far more contentious debate: whether mounting evidence that human behavior stems from biological, mechanistic causes suggests that our criminal law should dispense with retributivism altogether. It does so by using empirical evidence to construct the following argumentative framework upon which both empiricists and legal theorists might build. As the new science of human agency gradually illuminates an increasing number of links in the causal chain underlying given criminal behaviors, laypeople will view those behaviors as less blameworthy; and because the criminal law currently offers defendants limited means to avoid liability on the basis of diminished volitional capacity, laypeople's moral views will increasingly clash with criminal law outcomes. These moral mismatches will, in turn, precipitate diminished compliance, cooperation, and acquiescence with criminal laws, as well as increased general deviance. In short, available empirics suggest that changing public perceptions will bring adverse practical effects if the law remains static.

This argument—which amounts to an empirical prediction—supports reformists' charge, but cannot justify broad-based reforms to our justice system per se for two reasons. First, the looming threat of diminished moral credibility is one of many factors surely relevant to deciding whether retributivism's costs outweigh its benefits. Indeed, the age-old debate surrounding proper

200 *Id.* at 569-70, 573 (relying on "scientific and sociological studies" as well as diagnostic practice in psychiatry).

201 *Id.* at 570 (quoting *Thompson v. Oklahoma*, 487 U.S. 815, 835 (1988)).

202 *Id.* at 569-70.

203 *See id.* at 570. ("[T]he case for retribution is not as strong with a minor as with an adult. Retribution is not proportional if the law's most severe penalty is imposed on one whose culpability is diminished, to a substantial degree, by reason of youth and immaturity.").

justifications for criminal punishment spans centuries, oceans, and disciplines,²⁰⁴ and cannot be resolved by a single practical consideration. Thus, this Note's argument is best considered a single weight on the scale in favor of reform, not a debate-settling silver bullet. Second, methodological limitations in the research constrain the generalizability of present findings. The research does not tell us, for example, how frequently people are exposed to the new science of human agency, how long exposure to the new science of human agency affects individuals' moral judgments, or the extent to which moral mismatches drive general criminal deviance. Thus, the degree of the looming moral credibility problem is currently unknown. It would be premature to reorganize our criminal justice system based on data that is, in some sense, incomplete.

Nonetheless, the thesis of this Note exposes our criminal law's dependence on blame and responsibility as potentially antithetical to its own animating purposes. As such, it naturally invites speculation and conjecture on an enticing question this Note has, for reasons already discussed, hesitated to confront: what would a criminal justice system without the concepts of retribution, blame, and responsibility look like? In the last few lines before concluding, I succumb to temptation and offer a brief, 50,000-foot suggestion informed by the findings recounted above.

The broad-strokes solution is simply stated: craft a system whose sole focus is to serve the utilitarian goals of deterrence, rehabilitation, and incapacitation. As noted in Section I.A, a criminal convicted in this system—blameworthy or not—would receive a sentence designed to optimally benefit society. Importantly, however, this system would not necessarily dispense with retribution as an articulated goal of criminal punishment or remove the concepts of blame and responsibility “from the legal argot.”²⁰⁵ Instead, because available empirics reveal that human perception is one guarantor of (or cancer to) the system's effectiveness, this system would preserve those concepts to the extent that they serve, among other utilitarian ends, the function of producing outcomes in line with then-existing moral views. For example, a hypothetical jury explicitly instructed to consider desert and blameworthiness might hand down a verdict that better harmonizes with widely held moral beliefs.²⁰⁶ Similarly, this system would avoid handing down outlandishly severe punishments for comparatively minor offenses, even if doing so were considered a maximally

204 See, e.g., Matthew Haist, Comment, *Deterrence in a Sea of 'Just Deserts': Are Utilitarian Goals Achievable in a World of 'Limiting Retributivism'?*, 99 J. CRIM. L. & CRIMINOLOGY 789, 790-92 (2009) (providing a brief description of this debate's history, scope, and significance).

205 Eagleman, *supra* note 5.

206 In some jurisdictions, judges can and do instruct jurors to consider the purposes of punishment in making their decision. See Cotton, *supra* note 26, at 1317.

effective deterrent and rehabilitator, if that course of action sowed widespread discontent and a corresponding diminishment of the system's moral credibility that offset originally intended benefits. Thus, the concepts of retribution, blame, and responsibility would function as tools readily manipulated in service of utility, not, as is currently the case, bedrock precepts that limit criminal law's responsiveness to ever-changing moral tides.

This model is crude and oversimplified, but nonetheless addresses the core problem this Note has identified and offers the beginnings of a solution upon which others may build. Further, it is in some sense noncontroversial; reformists and conservationists agree that our system's utilitarian goals are worth preserving. Retribution, by contrast, has proved a key sticking point due to that concept's uncertain future. Thus, a model that repurposes retribution to serve utilitarian ends strikes a compromise between those unsure of the normative implications of the new science of human agency and those who champion that science as the harbinger of retributive justice's demise. Perhaps less importantly, it excavates the fate-versus-free will debate from its dusty, ancient seat of practical irrelevance.

A Breakthrough with the TPP: The Tobacco Carve-Out

Sergio Puig* and Gregory Shaffer†

The United States has made great progress in reducing tobacco consumption at home while spending taxpayer money to promote its consumption abroad.¹ While U.S. tobacco consumption rates haven't fallen dramatically since the 1960s, they are soaring in the developing world.² Today, about twenty percent of adults in the world smoke, and more than eighty percent of them live in low- and middle-income countries.³ As a result, tobacco could kill one billion people this century, and largely in these lower-income countries.⁴

Tobacco's global success is partly the result of free-trade agreements that

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1 Since the first Surgeon General's Report on tobacco use was published in 1964, adult smoking rates in the United States have decreased by more than half, from 42.4% in 1965 to 16.8% in 2014. See OFFICE OF THE SURGEON GEN., U.S. DEP'T OF HEALTH & HUMAN SERVS., THE HEALTH CONSEQUENCES OF SMOKING—50 YEARS OF PROGRESS: A REPORT OF THE SURGEON GENERAL 720 (2014); Ahmed Jamal et al., *Current Cigarette Smoking Among Adults—United States, 2005–2014*, 64 MORBIDITY & MORTALITY WKLY. REP. 1233, 1233 (2015).

2 See *Tobacco and the Developing World*, ACTION ON SMOKING & HEALTH 1 (2015), http://ash.org.uk/files/documents/ASH_126.pdf; WORLD HEALTH ORG., WHO REPORT ON THE GLOBAL TOBACCO EPIDEMIC, 2015: RAISING TAXES ON TOBACCO 11 (2015), http://apps.who.int/iris/bitstream/10665/178574/1/9789240694606_eng.pdf (reporting that over 80% of premature deaths from noncommunicable diseases occur in the developing world, and that tobacco represents “the largest preventable risk factor” for these diseases). But see Carl E. Bartecchi et al., *The Human Costs of Tobacco Use*, 330 NEW ENG. J. MED. 975, 975 (1994) (reporting former Surgeon General C. Everett Koop's statement that “cigarette smoking is the leading cause of preventable premature death in our society and the most important public health issue of our time”).

3 See WORLD HEALTH ORG., *supra* note 1, at 15. According to the World Health Organization, member states are grouped into four income groups (low, lower-middle, upper-middle, and high) based on the World Bank's list of analytical income classification of economies. See *Health Statistics and Information Systems: Definition of Region Groupings*, WORLD HEALTH ORG. (2016), http://www.who.int/healthinfo/global_burden_disease/definition_regions/en.

4 See WORLD HEALTH ORG., *supra* note 1, app.VII (reporting an age-standardized tobacco smoking rate of 21.1% in 2013 among persons aged at least fifteen years); *Tobacco Could Kill a Billion People This Century, UN Health Official Warns*, UN NEWS CTR. (Apr. 29, 2011), <http://www.un.org/apps/news/story.asp?NewsID=38240#.Vu7l3xlrKV4>.

mandate the removal of import taxes and other commercial restrictions on most goods, including tobacco products.⁵ Both Republican and Democratic administrations have supported the tobacco industry in trade deals and awarded federal subsidies to tobacco growers and exporters for eight decades.⁶ These generous subsidies were only ended (at least for now) in 2014.⁷ U.S. policymakers have long maintained that since cigarettes are legally sold in the United States and abroad, trade officials should treat the industry no differently in trade agreements.⁸ A 1990 congressional report issued at the dawn of major trade negotiations noted the “conflict . . . between U.S. trade goals and health policy objectives,” but to no avail.⁹

The tobacco ‘carve-out’ in the recently concluded Trans-Pacific Partnership Agreement (TPP) represents a historic shift.¹⁰ The carve-out permits TPP member countries to block corporations from using the ‘investor-state dispute settlement’ (ISDS) mechanism to receive compensation for commercial damages resulting

⁵ See, e.g., Robert Stumberg, *Safeguards for Tobacco Control: Options for the TPPA*, 39 AM. J.L. & MED. 382, 382-83 (2013). But cf. Jeffery Drope & Jenina Joy Chavez, *Complexities at the Intersection of Tobacco Control and Trade Liberalization: Evidence from Southeast Asia*, 24 TOBACCO CONTROL e128, e129 (2015) (pointing to some complex methodological issues in studying the effects of trade liberalization and the level of tobacco consumption).

⁶ Agricultural Adjustment Act of 1938, ch. 30, 52 Stat. 31; Tobacco Control Act, ch. 866, 48 Stat. 1275 (1934) (establishing price support and production adjustment for tobacco); For recent discussion on their elimination, see Emily McCord, *Tobacco Farmers Lose Longtime Safety Net*, NPR (Oct. 24, 2014), <http://www.npr.org/2014/10/24/357947259/tobacco-farmers-lose-longtime-safety-net>. In fact, since the 1960s countries like Malawi have complained about the effects of U.S. subsidies in global markets and on local production. See Statement by the Representative of Malawi Before the Council of Representatives for the General Agreement on Tariffs and Trade, United States Subsidy on Manufactured Tobacco (Nov. 6, 1967), https://www.wto.org/gatt_docs/English/SULPDF/90800173.pdf.

⁷ See McCord, *supra* note 6.

⁸ See, e.g., Thomas J. Bollyky, *The Tobacco Problem in U.S. Trade*, COUNCIL ON FOREIGN REL. (Sept. 5, 2013), <http://www.cfr.org/trade/tobacco-problem-us-trade/p31346>. But see Stan Sesser, *Opium War Redux*, NEW YORKER, Sept. 13, 1993, at 78, 79 (quoting Dr. James Mason, Assistant Secretary for Health in the U.S. Department of Health and Human Services under President George H.W. Bush, as saying: “Our country has been known for its humanitarian and health-related projects worldwide. This is a hundred and eighty degrees opposite. We’re talking about millions of lives—and that totally outweighs and overwhelms what we’ve accomplished in the humanitarian field. It’s outrageous for the United States to allow this misery and suffering to occur”).

⁹ U.S. GEN. ACCOUNTABILITY OFF., GAO/NSIAD-90-190, TRADE AND HEALTH ISSUES: DICHOTOMY BETWEEN U.S. TOBACCO EXPORT POLICY AND ANTISMOKING INITIATIVES 5 (1990), <http://www.gao.gov/assets/150/149076.pdf>.

¹⁰ See Jackie Calmes, *Trans-Pacific Partnership Is Reached, but Faces Scrutiny in Congress*, N.Y. TIMES (Oct. 5, 2015), <http://www.nytimes.com/2015/10/06/business/trans-pacific-partnership-trade-deal-is-reached.html>.

from tobacco control measures.¹¹ For the first time, an international commercial treaty treats tobacco companies exceptionally for selling—to quote from the World Health Organization—the “only legally available product that kills up to one half of its regular users.”¹²

The carve-out comes in the wake of two key trends. On the one hand, tobacco companies are strategically using international litigation, such as ISDS, to challenge tobacco control measures around the world, including bans of flavored cigarettes; marketing and advertising restrictions; labeling requirements of health risks; import and export taxes; price, import, and export controls; and brand registration recognition. Philip Morris is implicated in one-third of thirty-nine international cases tracked by a recent study.¹³ On the other hand, in part because of international cases involving tobacco, litigation has incited growing resistance to ISDS in the United States itself, a challenge politically advanced by Senator Elizabeth Warren, among others.¹⁴ ISDS is not the only international dispute-resolution mechanism, but it raises particular concerns since it is not an interstate mechanism, but rather directly grants foreign companies legal standing to bring claims against governments before ad hoc arbitration panels. In ISDS cases, both the company and the government select one of the arbitrators from among a specialized bar paid large sums to arbitrate the disputes. The arbitrators’ decisions

11 *Id.* Article 29.5 of the TPP reads:

A Party may elect to deny the benefits of Section B of Chapter 9 (Investment) with respect to claims challenging a tobacco control measure of the Party. Such a claim shall not be submitted to arbitration under Section B of Chapter 9 (Investment) if a Party has made such an election. If a Party has not elected to deny benefits with respect to such claims by the time of the submission of such a claim to arbitration under Section B of Chapter 9 (Investment), a Party may elect to deny benefits during the proceedings. For greater certainty, if a Party elects to deny benefits with respect to such claims, any such claim shall be dismissed.

Trans-Pacific Partnership Agreement, art. 29.5, at 29-9, Feb. 4, 2016,

<https://ustr.gov/sites/default/files/TPP-Final-Text-Exceptions-and-General-Provisions.pdf>.

12 *Tobacco Free Initiative (TFI): Tobacco Product Regulation*, WORLD HEALTH ORG. (2016), http://www.who.int/tobacco/industry/product_regulation/background/en.

13 See Sergio Puig, *Tobacco Litigation in International Courts*, 57 HARV. INT’L L.J. (forthcoming 2016) (finding, based on 39 cases brought before international courts and tribunals, that at least 13 cases (or 34% of the surveyed cases) either directly or indirectly (i.e., through an affiliated company) involved Philip Morris International).

14 See Elizabeth Warren, *The Trans-Pacific Partnership Clause Everyone Should Oppose*, WASH. POST (Feb. 25, 2015), https://www.washingtonpost.com/opinions/kill-the-dispute-settlement-language-in-the-trans-pacific-partnership/2015/02/25/ec7705a2-bd1e-11e4-b274-e5209a3bc9a9_story.html (describing ISDS panels as “rigged[] pseudo-courts” that favor multinational corporations at the expense of sovereign states and their citizens).

are not subject to appeal and national courts recognize their arbitral awards except on narrow grounds. ISDS claims have proliferated over the past decade, including against developed countries' regulatory practices, and they have incited increasing contestation of the legitimacy of the ISDS system.¹⁵

Current international litigation against Australia's recent tobacco regulation illustrates these trends.¹⁶ Mobilized primarily by Philip Morris,¹⁷ four countries are challenging before the World Trade Organization (WTO) an Australian law that mandates placing on all cigarette packages large graphic images of smoking's effects.¹⁸ The companies argue that the law violates their trademark rights, despite

15 See, e.g., David Schneiderman, *Investment Rules and the New Constitutionalism*, 25 LAW & SOC. INQUIRY 757, 758-59 (2000); see also Anthony DePalma, *NAFTA's Powerful Little Secret; Obscure Tribunals Settle Disputes, but Go Too Far, Critics Say*, N.Y. TIMES (Mar. 11, 2001), <http://www.nytimes.com/2001/03/11/business/nafta-s-powerful-little-secret-obscure-tribunals-settle-disputes-but-go-too-far.html> (describing early criticisms of the role of international tribunals between parties to the North American Free Trade Agreement); Letter from Erwin Chemerinsky, Dean, Univ. of Cal., Irvine Sch. of Law, et al., to Sen. Mitch McConnell et al. (Mar. 11, 2015), <http://www.afj.org/wp-content/uploads/2015/03/ISDS-Letter-3.11.pdf> (collecting support from a broad group of law professors against inclusion of ISDS provisions in the TPP). See generally GUS VAN HARTEN, *INVESTMENT TREATY ARBITRATION AND PUBLIC LAW* (2007) (describing various features of the modern system of investment treaty arbitration).

16 *Tobacco Plain Packaging Act 2011* (Cth) s 20(1), (2) (Austl.).

17 See Myron Leving, *Tobacco Industry Uses Trade Pacts To Try To Snuff out Anti-Smoking Laws*, NBC NEWS (Nov. 29, 2012, 12:14 AM), http://openchannel.nbcnews.com/_news/2012/11/29/15519194-tobacco-industry-uses-trade-pacts-to-try-to-snuff-out-anti-smoking-laws. In most trade agreements, including the WTO, any State party to the treaty may initiate an enforcement action. Governments tend to exercise restraint in the initiation of proceedings after carefully assessing the balance between the likely benefits, including market access and the costs of bringing an action. In the Australian case, British American Tobacco initially convinced Ukraine—with no direct interest in the Australian tobacco market—to bring a complaint. (After the 2014 revolution, the new government of Ukraine changed course and withdrew the case). Philip Morris convinced the Dominican Republic, which has some general interest in tobacco regulation but no significant amount of tobacco exports to Australia. Philip Morris is currently paying the legal fees of bringing the case, which is arguably a standard practice in WTO disputes. See Sergio Puig, *The Merging of International Trade and Investment Law*, 33 BERKELEY J. INT'L L. 1, 33 & n.115 (2015). For background on the relation of private companies with governments in the bringing of WTO cases, see generally GREGORY SHAFFER, *DEFENDING INTERESTS: PUBLIC-PRIVATE PARTNERSHIPS IN WTO LITIGATION* (2003).

18 The four countries are Cuba, Indonesia, Honduras, and the Dominican Republic. See, e.g., *Dispute Settlement, Australia—Certain Measures Concerning Trademarks, Geographical Indications and Other Plain Packaging Requirements Applicable to Tobacco Products and Packaging*, WORLD TRADE ORG. (May 5, 2014), http://www.wto.org/english/tratop_e/dispu_e/cases_e/ds435_e.htm (concerning matters labeled DS435, DS441, DS458, and DS467). At one point, Ukraine also participated but has suspended its involvement after one Ukrainian Member of Parliament expressed confusion

losing this same issue before Australia's High Court.¹⁹ Simultaneously, Philip Morris created a subsidiary to sue for damages before an ISDS arbitral panel under a treaty between Australia and Hong Kong on the grounds that Australia's law constitutes an illegal 'taking' of its brands.²⁰ Philip Morris recently lost the ISDS arbitration on jurisdictional grounds—an unsatisfactory outcome that failed to clarify the proper interaction between investment treaties and tobacco control efforts. As a result, tobacco companies can still use the threat of arbitration against countries considering tobacco control measures.²¹ The WTO case, moreover, continues.

The industry argues that the TPP carve-out unfairly targets tobacco products, and it has promised to sink the TPP in the U.S. Congress.²² We assert that the

when she learned that her country was a part of the litigation. See Norman Hermant, *Ukraine Attacks Australia's Plain Packaging Laws*, AUSTL. BROADCASTING CORP. (Apr. 17, 2015), <http://www.abc.net.au/lateline/content/2012/s3479769.htm>.

19 *JT Int'l SA v Commonwealth* [2012] HCA 43 (Austl.). In the Australian courts, the plaintiffs argued that the provisions were invalid because they constituted a taking of their trademarks on "[un]just terms." *Id.* ¶ 2. The Australian High Court denied their claim, finding that the Act only controls the way tobacco is marketed. *Id.* ¶ 44.

20 Notice of Arbitration, ¶¶ 7.2-7.3, *Philip Morris Asia v. Commonwealth of Australia* (Nov. 21, 2011), <https://www.ag.gov.au/Internationalrelations/InternationalLaw/Documents/Philip%20Morris%20Asia%20Limited%20Notice%20of%20Arbitration%2021%20November%202011.pdf>; see also *Bilateral Investment Treaty (BIT) Arbitration: Philip Morris Asia Limited & the Commonwealth of Australia*, PHILIP MORRIS INT'L http://www.pmi.com/eng/media_center/company_statements/Pages/bilateral_investment_treaty.aspx (last visited May 16, 2016) (listing Philip Morris's claims against Australia's plain-packaging rules).

21 The tribunal's detailed reasoning for rejecting jurisdiction over Philip Morris's claims is not yet available. See Jarrod Hepburn & Luke Eric Peterson, *Australia Prevails in Arbitration with Philip Morris over Tobacco Plain Packaging Dispute*, INV. ARB. REP. (Dec. 17, 2015), <http://www.iareporter.com/articles/breaking-australia-prevails-in-arbitration-with-philip-morris-over-tobacco-plain-packaging-dispute/>. Phillip Morris also filed a case against Uruguay under the Switzerland-Uruguay bilateral investment treaty before the International Centre for Settlement of Investment Disputes regarding legislation requiring all cigarettes manufacturers to adopt a single presentation on packages. This case remains pending. See *Philip Morris Brands Sàrl v. Oriental Republic of Uru.*, ICSID Case No. ARB/10/7, Decision on Jurisdiction, ¶¶ 5-6 (July 2, 2013), https://icsid.worldbank.org/ICSID/FrontServlet?requestType=CasesRH&actionVal=showDoc&docId=DC3592_En&caseId=C1000.

22 See Alex Rogers, *Election Politics Might Delay Vote on Pacific Trade Accord*, NAT'L J., Nov. 5, 2015, <http://www.theatlantic.com/politics/archive/2015/11/election-politics-might-delay-vote-on-pacific-trade-accord/454998>. The American Chamber of Commerce representative said: "[S]ingling out tobacco [will] open a Pandora's box as other governments go after their particular bêtes noires." Danny Hakim, *U.S. Chamber of Commerce Works Globally To Fight Anti-Smoking Measures*, N.Y. TIMES (June 30, 2015), <http://www.nytimes.com/2015/07/01/business/international/us-chamber-works-globally-to->

tobacco carve-out is far from unfair. It comes in response to increasing industry litigation used to chill tobacco regulation abroad. As documented by the Campaign for Tobacco Free Kids, tobacco companies have threatened international litigation against several poor countries considering tobacco control measures, all of which bowed to industry pressure and abandoned the intended legislation.²³ Moreover, the carve-out applies only to ISDS, a venue considered more problematic than other international forums because companies have direct access to arbitral tribunals and there is no governmental screen between the companies and their introduction of an international claim. With ISDS there is thus a greater likelihood of overzealous litigation and private pressure behind the scenes through the threat of arbitration. Any of the current twelve signatory parties to the TPP can still bring claims (either before a WTO or a TPP panel) if they believe another governmental party to the treaty is regulating tobacco products for trade-protectionist reasons rather than to protect public health.

Unimpressed, advocates long concerned about international commercial deals and socially excessive litigation initiated by industry criticize the carve-out for being ‘too little, too late.’²⁴ We affirm, however, that the Obama Administration’s break with the tobacco industry is groundbreaking. With this move, President Obama risks his legacy pact since some otherwise ‘pro-trade’ Republican legislators have threatened to join many Democrats and vote against the TPP because of the tobacco carve-out.²⁵ In past trade deals, the interests of tobacco producers were put above those of the public. The TPP carve-out hopefully begins a new trend to accommodate public health concerns in trade deals. It could help pave the way toward curtailing expansive intellectual property provisions, and the prospects of aggressive litigation under them, that empower large pharmaceutical

fight-antismoking-measures.html.

23 Sabrina Tavernise, *Tobacco Industry Tactics Limit Poorer Nations’ Smoking Laws*, N.Y. TIMES (Dec. 13, 2013), <http://www.nytimes.com/2013/12/13/health/tobacco-industry-tactics-limit-poorer-nations-smoking-laws.html>.

24 See, e.g., Gary Fooks & Anna B. Gilmore, *International Trade Law, Plain Packaging and Tobacco Industry Political Activity: The Trans-Pacific Partnership*, 23 TOBACCO CONTROL e1, e5-e6 (2014); Joseph Stiglitz: *Under TPP, Polluters Could Sue U.S. for Setting Carbon Emissions Limits*, DEMOCRACY NOW (Oct. 27, 2015), http://www.democracynow.org/2015/10/27/joseph_stiglitz_under_tpp_polluters_could (arguing generally against ISDS, in part because of its use to neutralize tobacco control measures in Uruguay and Australia).

25 See Calmes, *supra* note 10. According to some sources, Ambassador Michael Froman, the current U.S. Trade Representative, was an important supporter of the carve-out. See Adam Behsudi, *Will the Trans-Pacific Deal Go up in Tobacco Smoke? The Ire of McConnell and Other Tobacco-State Lawmakers Throws a Wrench into the Negotiations*, POLITICO (Aug. 12, 2015, 1:41 PM), <http://www.politico.com/story/2015/08/will-trans-pacific-trade-deal-go-up-in-smoke-over-anti-tobacco-proposal-121272>.

companies against governmental interests and thus compromise public health.²⁶

The TPP could have gone further by exempting tobacco from tariff cuts. We would support this exemption, especially if coupled with consumption taxes that would raise revenue and reduce demand, particularly in poor countries like Vietnam.²⁷ Nonetheless, public health advocates should move beyond the claim that the TPP is ‘too little, too late.’²⁸ The TPP tobacco carve-out is an underappreciated, critical first step that existing and future trade and investment agreements should also adopt. The United States already has free trade agreements with many TPP countries, such as Mexico and Canada under the North American Free Trade Agreement (NAFTA), and these agreements grant ISDS rights to tobacco companies.²⁹ These ISDS allowances will continue to coexist unless the agreeing governments amend the relevant provisions or explicitly provide for their replacement. The United States should turn this TPP carve-out into official U.S. policy for all trade and investment agreements, including NAFTA. This breakthrough should be generalized so that trade and investment policy always complement, rather than subvert, public health goals.

26 See Amy Kapczynski, *The Trans-Pacific Partnership Is It Bad for Your Health?*, 373 NEW ENG. J. MED. 201 (2015).

27 See Michele Goodwin, Sergio Puig & Gregory Shaffer, *Watch Out, Joe Camel is Back, Tobacco and the TPP*, HUFFINGTON POST (Apr. 30, 2015), http://www.huffingtonpost.com/michele-goodwin/watch-out-joe-camel-is-ba_b_7177592.html. There are currently about 5000 tobacco farmers in the United States. See 1 NAT’L AGRICULTURAL STATISTICS SERV., U.S. DEP’T OF AGRICULTURE, 2012 CENSUS OF AGRICULTURE: UNITED STATES SUMMARY AND STATE DATA 559 tbl.44 (2014), https://www.agcensus.usda.gov/Publications/2012/Full_Report/Volume_1,_Chapter_1_US/us_v1.pdf. Hence, the impact on U.S. jobs would likely be fairly minimal.

28 See, e.g., James Surowiecki, *The Corporate-Friendly World of the T.P.P.*, NEW YORKER (Oct. 6, 2015), <http://www.newyorker.com/news/daily-comment/the-corporate-friendly-world-of-the-t-p-p> (noting that tobacco is “hardly the only industry that raises serious health and environmental concerns” and questioning why these other industries should be allowed to use the ISDS process).

29 For discussion of NAFTA, see Daniel Price, *Some Observations on Chapter Eleven of NAFTA*, 23 HASTINGS INT’L & COMP. L. REV. 421, 426-27 (2000). Unlike the TPP, Chapter 11 of NAFTA allows government policies, including tobacco control measures, to be challenged through investor-state arbitration. *Id.*