APPLYING THE HEALTH JUSTICE FRAMEWORK TO DIABETES AS A COMMUNITY-MANAGED SOCIAL PHENOMENON

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INTRODUCTION

In East Harlem, it is possible to take any simple nexus of people—the line at an A.T.M., a portion of a postal route, the members of a church choir—and trace an invisible web of diabetes that stretches through the group and out into the neighborhood, touching nearly every life with its menace.1

Ten years ago, the New York Times published “Bad Blood,” a series of articles examining the impact of diabetes on the residents of New York City.2 In the years that followed, New York pioneered a series of groundbreaking legal interventions,3 including implementing measures to track diabetes management at the population level,4 mandating calorie-count menu labeling at chain restaurants,5 and

5 See N.Y.C. DEPT’ OF HEALTH & MENTAL HYGIENE, NOTICE OF ADOPTION OF AN AMENDMENT (§ 81.50) TO ARTICLE 81 OF THE NEW YORK CITY HEALTH CODE 3 (2006), https://ia601001.us.archive.org/15/items/361711-nyc-regulation-81-50.notice-of-adoption-12-2006/361711-nyc-regulation-81-50.notice-of-adoption-12-2006.pdf (proposing that “[f]ood service establishments shall post on menu boards and menus the calorie content values (in kcal) that have been made publicly available [by or on behalf of the food service
capping the container size for sugary drinks. These measures, and others enacted at the local, state, and federal level, indicate the beginnings of a subtle, yet crucial, shift of perspective on diabetes over the course of the last decade: from viewing diabetes primarily in individualistic terms as a self-managed disease to understanding it as a social phenomenon managed at the community level.


establishment] for each menu item next to the listing of each menu item.”). The 2006 version of § 81.50 was struck down by the U.S. District Court for the Southern District of New York on the grounds that it was preempted by federal nutrition labeling laws. However, the Board of Health adopted a revised version of the amendment in 2008, N.Y.C. HEALTH CODE § 81.50, which was upheld by the Second Circuit Court of Appeals in the face of preemption and First Amendment challenges. See N.Y. State Rest. Ass’n v. N.Y. City Bd. of Health, 509 F. Supp. 2d 351, 353 (S.D.N.Y. 2007); N.Y. State Rest. Ass’n v. N.Y. City Bd. of Health, 556 F.3d 114 (2d Cir. 2009).

6 See N.Y.C. DEPT OF HEALTH & MENTAL HYGIENE, NOTICE OF ADOPTION OF AN AMENDMENT (§ 81.53) TO ARTICLE 81 OF THE N.Y.C. HEALTH CODE 1 (2012), http://www.nyc.gov/html/doh/downloads/pdf/notice/2012/notice- adoption-amend-article81.pdf (“A food service establishment may not sell, offer, or provide a sugary drink in a cup or container that is able to contain more than 16 fluid ounces.”). The measure was ultimately struck down by the state supreme court on state administrative law grounds. See N.Y. Statewide Coal. of Hispanic Chambers of Commerce v. N.Y.C. Dep’t of Health & Mental Hygiene, 16 N.E.3d 538, 541 (N.Y. 2014).

7 Diabetes mellitus refers to a group of chronic metabolic disorders that are characterized by hyperglycemia (high blood sugar). These disorders are broadly categorized into two main types, based on the process that leads to hyperglycemia. Type 1 diabetes only accounts for about 5–10% of all cases of diabetes in the United States, but accounts for about 80% of cases diagnosed under age twenty. Type 1 diabetes involves a total lack of insulin, a hormone that triggers muscle and other tissues to take up glucose from the blood. It is often, but not always, ascribable to an autoimmune process whereby the body’s immune cells destroy the beta cells in the pancreas that produce insulin, eventually eliminating insulin production altogether. Type 2 diabetes accounts for about 90–95% of all U.S. cases, but only about 20% of cases diagnosed under age twenty. Type 2 diabetes involves resistance to insulin: insulin is produced, but the body’s tissues do not respond to it effectively. The body might ramp up insulin production to adjust for the decreased response, maintaining normal blood sugar at least in the short-term. Over time, however, insulin production is not able to keep up with increased demand and blood glucose increases, resulting in diabetes. See Alvin C. Powers, Diabetes Mellitus: Diagnosis, Classification, and Pathophysiology, in 2 HARRISON’S PRINCIPLES OF INTERNAL MEDICINE 2399, 2400, 2404 (Dennis L. Kasper et al. eds., 19th ed. 2015).

8 See Number (in Millions) of Civilian, Noninstitutionalized Persons with Diagnosed Diabetes, United States, 1980–2011, CTRS. FOR DISEASE CONTROL & PREVENTION, http://www.cdc.gov/diabetes/statistics/prev/national/figpersons.htm (last visited July 16, 2016) (data from the National Health Interview Survey analyzed by the Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Diabetes.
Currently, about 10% of the U.S. population has diabetes and about 37% of adults have pre-diabetic blood sugar levels. The dramatic rise in prevalence of type 2 diabetes and pre-diabetes is attributable to the aging of the population, decreasing physical activity, and increasing prevalence of overweight and obesity. The prevalence is considerably higher among some subgroups, suggesting the importance of social determinants that influence the relative affordability and convenience of different dietary patterns, the effort required to integrate physical activity into daily life, and the sense of social and emotional wellbeing that affects individual choices about food and exercise, while also influencing blood sugar control more directly.

The rising prevalence of diabetes presents daunting challenges to the health system. Average medical expenditures for people with diagnosed diabetes are 2.3 times higher than for people without diabetes, amounting to $176 billion per year in direct medical costs. These costs are disproportionately borne by public insurance programs: about 14% of Medicaid beneficiaries, 20% of Medicare-only beneficiaries, and more than 30% of dual eligible, covered by both Medicare and Medicaid, have diagnosed diabetes. Poor glycemic control indicates that in 1990 there were 6.6 million Americans who had been diagnosed with diabetes, in 2000 there were 12 million, and in 2010 there were 20.8 million. 9 The Centers for Disease Control and Prevention (CDC) estimates that as of 2012, 20.1 million Americans had been diagnosed with diabetes, and more than 8 million more were living with undiagnosed diabetes. Additionally, more than 80 million additional American adults had intermediate blood glucose levels classifying them as pre-diabetic. 10

The factors contributing to an equally dramatic increase in type 1 diabetes and opportunities for prevention are much less well understood. Id. at 2403 ("Worldwide, the incidence of type 1 [diabetes mellitus] is increasing at the rate of 3–4% per year for uncertain reasons.").

See infra Part I.D and accompanying notes.

Powers, supra note 7, at 2400. The factors contributing to an equally dramatic increase in type 1 diabetes and opportunities for prevention are much less well understood. Id. at 2403 ("Worldwide, the incidence of type 1 [diabetes mellitus] is increasing at the rate of 3–4% per year for uncertain reasons.").

See infra Part I.D and accompanying notes.

11 See infra Part I.D and accompanying notes.

12 NATIONAL DIABETES STATISTICS REPORT, supra note 9, at 8.

control among diagnosed diabetics\textsuperscript{14} suggests that the health system is failing to provide much-needed support.

However, there are also opportunities to curb this trend. Relatively small decreases in daily calorie intake, increases in physical activity, and modest weight loss can slow, or even stop, the transition from impaired glucose tolerance to type 2 diabetes\textsuperscript{15} and can delay, or even obviate, the need for pharmacological interventions.\textsuperscript{16} Effective management with diet, physical activity, and medication can also slow or prevent the onset of complications.\textsuperscript{17}

Traditionally, prevention and control of diabetes have been viewed primarily as a matter of personal responsibility. As scientific understanding of the social determinants of health has become more sophisticated, however, many experts have questioned the effectiveness of individualistic strategies that emphasize urging at-risk individuals to change their habits, rather than making changes at the community level to facilitate healthier lifestyles for everyone.\textsuperscript{18}

\begin{itemize}
\item \textsuperscript{14} See Mohammed K. Ali et al., Characteristics Associated with Poor Glycemic Control Among Adults with Self-Reported Diagnosed Diabetes—National Health and Nutrition Examination Survey, United States, 2007–2010, 61 MORTALITY & MORBIDITY WkLY. Rep. 32, 33 (2012) (finding that about 13% of U.S. adults who reported that they had been diagnosed with diabetes exhibited poor glycemic control, with higher rates of poor glycemic control among the uninsured (28.5%), those aged eighteen to thirty-nine (24.2%), non-Hispanic blacks (18.7%), and Hispanics (18.8%).
\item \textsuperscript{15} See Look AHEAD Research Group et al., Long-term Effects of a Lifestyle Intervention on Weight and Cardiovascular Risk Factors in Individuals with Type 2 Diabetes Mellitus: Four Year Results of the Look AHEAD Trial, 170 ARCH. INTERNAL MED. 1566, 1566 (2010).
\item \textsuperscript{16} Jim I. Mann & Alexandra Chisolm, Dietary Management of Diabetes Mellitus in Europe and North America, in INTERNATIONAL TEXTBOOK OF DIABETES MELLITUS 577 (Ralph A. DeFronzo et al. eds., 4th ed. 2015); Thomas Yates & Melanie J. Davies, Prevention of Type 2 Diabetes, in INTERNATIONAL TEXTBOOK OF DIABETES MELLITUS 550 (Ralph A. DeFronzo et al. eds., 4th ed. 2015).
\item \textsuperscript{17} See Mann & Chisolm, supra note 16, at 577; Yates & Davies, supra note 16, at 550; Henrik Galbo & Erik A. Richter, Exercise, in INTERNATIONAL TEXTBOOK OF DIABETES MELLITUS 589 (Ralph A. DeFronzo et al. eds., 4th ed. 2015); Susan L. Samson & Alan J. Garber, Metformin and Other Biguanides: Pharmacology and Therapeutic Usage, in INTERNATIONAL TEXTBOOK OF DIABETES MELLITUS 646–48 (Ralph A. DeFronzo et al. eds., 4th ed. 2015).
\item \textsuperscript{18} See, e.g., Leonard Jack, Jr. et al., Social Determinants of Health in Minority Populations: A Call for Multidisciplinary Approaches to Eliminate Diabetes-Related Health Disparities, 25 DIABETES SPECTRUM 9, 9–10 (2012) ("The predominant paradigm used in chronic disease prevention and control rests on the traditional and hard-held belief that individuals are solely responsible for adopting and maintaining modifications in lifestyle practices . . . .")
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Furthermore, as we shift toward a more collective approach to health care financing, interest in evidence-based approaches to disease prevention and management—in the clinical context, as well as in the community—is growing. The Patient Protection and Affordable Care Act ("ACA")\(^{19}\) includes several provisions that directly address gaps in diabetes prevention, screening, care, and treatment,\(^{20}\) as well as more broadly applicable provisions aimed at promoting community-level prevention.\(^{21}\)

Understanding the link between social determinants of health and diabetes can lead to the identification of nontraditional strategies by using nontraditional partners and identifying opportunities for improving or preventing negative health outcomes in communities affected by the inequitable conditions that create them.\(^{16}\) The Social Determinants of Diabetes and the Challenge of Prevention, INT’L DIABETES FED’N, http://www.idf.org/node/23947?language=ru (last visited July 16, 2016) ("There is a great deal of interest in approaches to the prevention of type 2 diabetes that target people who are at high risk. However, targeting individuals at high-risk is at best likely to have a moderate impact on the prevalence of type 2 diabetes. There are two reasons for this. Firstly, it is difficult to translate approaches from complex and well-resourced research studies into the ‘real world’, including being able to find and recruit people who are at high-risk and deliver effective prevention. Secondly, a substantial proportion of diabetes will arise in people who are not identified as high-risk, and who would not, therefore, be recruited for such preventive interventions. The real challenge is to tackle the underlying determinants of type 2 diabetes globally, which, put simply, means modifying environments to make them less obesogenic. This challenge is as great if not greater than reducing tobacco consumption. Modifying the obesogenic environment is likely to require a broad range of policy measures across multiple sectors."); Yates & Davies, supra note 16, at 550–63.


\(^{20}\) For example, the ACA obligates private health plans offered on subsidized Health Insurance Exchanges, as well as privatized Medicaid “benchmark” plans to provide an Essential Health Benefit package, including prescription drugs, laboratory services, preventive and wellness services, chronic disease management, and pediatric services. It also mandates first-dollar coverage (no copay, coinsurance, or deductible may be applied) for preventive services. 42 U.S.C. § 300gg-13 (2012); Group Health Plans and Health Insurance Issuers Relating to Coverage of Preventive Services Under the ACA, 76 Fed. Reg. 46,621, 46,626 (Aug. 3, 2011) (amendments to be codified at 45 C.F.R. pt. 147) (announcing the interim final rule regarding coverage of preventive health services); see also Final Recommendation Statement: Abnormal Blood Glucose and Type 2 Diabetes Mellitus: Screening, U.S. PREVENTIVE SERVS. TASK FORCE (Oct. 27, 2015), http://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/screening-for-abnormal-blood-glucose-and-type-2-diabetes ("[Covered services include] screening for abnormal blood glucose as part of cardiovascular risk assessment in adults aged 40 to 70 years who are overweight or obese, while patients with abnormal blood glucose are referred to intensive behavioral counseling interventions.").

\(^{21}\) For example, the ACA established a National Prevention, Promotion, and Public Health Council, a Prevention and Public Health Fund, and a Community Transformation Grant
This Article argues that health law and policy can and should support a nascent reorientation—consistent with the health justice framework I have developed in previous articles—of the health system’s response to diabetes, from understanding diabetes primarily as a self-managed medical disorder, to responding to it as part of a broader social phenomenon managed at the community level. Part I of this Article describes the challenges posed by particular characteristics of diabetes, with an emphasis on its chronic and progressive nature, the common understanding that it is primarily a self-managed disorder, and the insidious nature of its complications. Part II describes the existing legal and policy landscape for responding to diabetes, including with respect to prevention, medical management, health insurance coverage, and discrimination. Part III introduces health justice as a framework for eliminating disparities, and points to indications within the existing law and policy landscape of a reorientation toward understanding diabetes as a social phenomenon managed primarily at the community level. I argue that these developments can and should be reinforced through law reform, litigation, policy implementation, and scholarship consistent with the health justice framework.

I. DIABETES: AN IMPENDING CRISIS FOR THE HEALTH SYSTEM

A. Diabetes is Chronic and Progressive

Diabetes is diagnosed when blood glucose levels or hemoglobin A1c levels rise above a defined threshold, but the disease is best...
understood in terms of a progression from normal glucose tolerance, to pre-diabetic impaired glucose tolerance (also known as intermediate hyperglycemia), to diabetes controlled with oral medications, to diabetes that requires insulin for control of blood sugar.\textsuperscript{24} It is possible for a person to move back and forth along this spectrum, from pre-diabetic, to diabetic, and back again.\textsuperscript{25} But for the vast majority of patients, the disease is progressive, eventually leading to insulin dependence.

The U.S. health system is ill-equipped to tackle chronic diseases in general, but diabetes in particular.\textsuperscript{26} “[O]ur delivery and payment systems ironically provide largely acute care tools to deal with the problems of chronic disease.”\textsuperscript{27} High-quality, cost-effective management of chronic conditions like diabetes depend on primary care services.\textsuperscript{28} Yet, the U.S. has fewer primary care physicians per capita than most industrialized countries.\textsuperscript{29} Proactive care management by multidisciplinary teams—emphasizing identification

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\textsuperscript{24} See Powers, supra note 7, at 2399.

\textsuperscript{25} Id.

\textsuperscript{26} See, e.g., Trajko Bojadzievski & Robert A. Gabbay, \textit{Patient-Centered Medical Home and Diabetes}, 34 DIABETES CARE 1047, 1047 (2011) (“The current model of health care delivery is designed to address acute health problems and is based on episodic face-to-face interactions between health care provider and patient, which often do not address the needs of chronically ill individuals. Diabetes is a well-documented example of a high cost prevalent chronic illness where a significant quality chasm exists.”).

\textsuperscript{27} Albert L. Siu et al., \textit{The Ironic Business Case for Chronic Care in the Acute Care Setting}, 28 HEALTH AFF. 113, 114 (2009).

\textsuperscript{28} People who live in regions where there are adequate numbers of primary care physicians have better health outcomes and lower health care costs. See, e.g., Johan Hansen et al., \textit{Living in a Country with a Strong Primary Care System is Beneficial to People with Chronic Conditions}, 34 HEALTH AFF. 1531 (2015); Barbara Starfield et al., \textit{Contribution of Primary Care to Health Systems and Health}, 83 MILBANK Q. 457 (2005); Katherine Baicker & Amitabh Chandra, \textit{Medicare Spending, the Physician Workforce, and Beneficiaries’ Quality of Care}, 23 HEALTH AFF. 184 (2004); Christopher B. Forrest & Barbara Starfield, \textit{The Effect of First Contact Care with Primary Care Clinicians on Ambulatory Health Care Expenditures}, 43 J. FAM. PRACTICE 40 (1996); Andrew B. Bindman, \textit{Preventable Hospitalizations and Access to Health Care}, 274 JAMA 305 (1995); Sheldon Greenfield et al., \textit{Variations in Resource Utilization Among Medical Specialties and Systems of Care: Results from the Medical Outcomes Study}, 267 JAMA 1624 (1992).

\textsuperscript{29} Barbara Starfield et al., \textit{The Effects of Specialist Supply on Populations’ Health: Assessing the Evidence}, 24 HEALTH AFF. 97, 101 (2005).
of patients at risk for poor outcomes, comprehensive assessment of each individual’s needs, development and implementation of an individual care plan, and monitoring of outcomes coordinated by a case manager, typically a nurse—is also crucial to good diabetes care.\textsuperscript{30} Yet, reimbursement for such services is traditionally lower than reimbursement for treatment of complications after they have occurred.\textsuperscript{31} Although more physician practice groups are adopting evidence-based care management practices, prevalence of these practices is still quite low.\textsuperscript{32} It is perhaps not surprising that many people with diabetes in the U.S. are not within recommended parameters for blood sugar control.\textsuperscript{33}

B. Diabetes is Self-Managed

Diabetes self-management education has long been regarded as “the cornerstone of care” for the disease.\textsuperscript{34} Indeed, most of the multidisciplinary care management practices discussed above, and many community-based interventions, are focused on improving

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\textsuperscript{31} See Lenard I. Lesser et al., Comparison Between US Preventive Services Task Force Recommendations and Medicare Coverage, 9 ANNALS FAM. MED. 44 (2011).

\textsuperscript{32} In 2013, only 9% of physician group practices employed nurse care managers for chronic conditions (up from 3% in 2009), while 31% employed non-physician staff for patient education on chronic conditions (up from 19% in 2009), and 33% provided patient reminders for prevention of and follow-up for chronic conditions (up from 28% in 2009). James A. Wiley et al., Managing Chronic Illness: Physician Practices Increased the Use of Care Management and Medical Home Processes, 34 HEALTH AFF. 78 (2015) (reporting increases in the prevalence of patient-centered medical home index components over time for small and medium-sized physician practices).

\textsuperscript{33} See Ali et al., supra note 14, at 2.

\textsuperscript{34} Carol Mensing et al., National Standards for Diabetes Self-Management Education Programs, 21 DIABETES EDUC. 189, 189 (1995).
\end{flushleft}
patients’ ability to manage their own disease on a day-to-day basis. The balance between the rate at which glucose enters the bloodstream and the rate at which it is taken up by the tissues and converted to energy is affected by a wide range of influences, including diet, physical activity, concurrent illness, sleep patterns, and psychosocial stress. Because the window in which insulin dosage is effective and not fatal fluctuates, frequent monitoring of blood sugar is necessary to adjust the dosage as needed.

Intensive management of blood sugar substantially reduces the risk of eye, nerve, kidney, and heart disease caused by diabetes. But intensive management may require blood glucose testing four or more times a day, injecting insulin three or more times daily, adjusting insulin dosage in response to food intake and exercise, adhering to a diet and exercise plan, and monthly visits to a health care team.


36 See generally Gisela Wilcox, Insulin and Insulin Resistance, 26 CLINICAL BIOCHEM REV. 19 (2005) (primarily discussing the role of insulin resistance in obesity and diabetes prevalence, but also exploring the effects of physical activity, diet, work, socialization, and sleep patterns on blood glucose levels).


38 See Diabetes Control & Complications Trial Research Grp., DCCT: The Effect of Intensive Treatment of Diabetes on the Development and Progression of Long-Term Complications in Insulin-Dependent Diabetes Mellitus, 329, 329 NEW ENG. J. MED. 977 (1993) (describing the DCCT protocol, which was associated with a more than 75% reduction in eye disease, 66% reduction in nerve disease, and 50% reduction in kidney disease); Diabetes Control & Complications Trial Research Grp. & Epidemiology of Diabetes Interventions and Complications Study Research Grp., Intensive Diabetes Treatment and Cardiovascular Disease in Patients with Type 1 Diabetes, 353 NEW ENG. J. MED. 2643, 2643–44 (2005) (reporting the results of the EIDC study, finding a 42% reduction in all cardiovascular disease events and a 57% reduction in non-fatal heart attack, stroke, or death from cardiovascular causes).

tests to monitor sugar levels and daily medication regimens, eventually including insulin injections for most patients, are uncomfortable and interfere with daily life, and insulin requires refrigeration and access to safe injection equipment. Also, medical appointments to prevent, monitor, and manage complications of diabetes (discussed infra) quickly add up, interfering with work schedules and other obligations. Additionally, people with diabetes are instructed to inspect their feet carefully every day for minor injuries and infections, which they might not notice otherwise.

The time, expense, and social support required to manage diabetes mean that, for many, diabetes is not so much a self-managed disease as a family-managed disease. Spouses, adult children, and others who care for people with diabetes are relied upon to monitor diet, exercise, foot care, blood sugar testing, and medication regimens, and to provide transportation and support for the multitude of doctor’s appointments and procedures that many diabetics must endure. People with diabetes are at increased risk for other chronic conditions, which they typically experience simultaneously, including depression and heart disease, making them particularly dependent on the social support provided by family and friends.

40 See, e.g., Monitor Your Diabetes, supra note 37 (“You may need to check before and after eating, before and after physical activity, before bed, and sometimes in the middle of the night. Make sure to keep a record of your blood glucose self-checks.”).


43 See generally Joni L. Strom & Leonard E. Egede, The Impact of Social Support on Outcomes in Adult Patients with Type 2 Diabetes: A Systematic Review, 12 CURRENT DIABETES REPS. 769 (2012) (finding that higher levels of social support are associated with improved clinical outcomes, reduced psychosocial symptoms, and adoption of healthy behaviors).

44 See Ryan J. Anderson et al., The Prevalence of Comorbid Depression in Adults with Diabetes, 24 DIABETES CARE 1069, 1074 (2001) (finding that diabetics were twice as likely to experience depression than non-diabetics); Emerging Risk Factors Collaboration, Diabetes Mellitus, Fasting Blood Glucose Concentration, and Risk of Vascular Disease: A Collaborative Meta-Analysis of 102 Prospective Studies, 375 LANCET 2215, 2220 (2010) (finding that diabetes is associated with a two-fold increase in risk for a wide range of vascular diseases).
C. The Complications of Diabetes are Insidious and Devastating

Over a span of years, metabolic abnormalities associated with diabetes may result in microvascular complications (retinopathy, kidney disease, and damage to the peripheral nerves) and macrovascular complications (including stroke, heart attack, and peripheral arterial disease). These complications are potentially devastating, resulting in blindness, dependence on kidney dialysis, amputation, and, for a significant proportion of people with diabetes, premature death. They are also typically insidious, progressing so gradually over the course of years or decades that they can be easy to miss until significant and permanent damage has occurred.

Diabetes is the leading cause of lower extremity amputation in the U.S. Together, high blood sugar and microvascular and macrovascular complications may result in gangrene, while diminished sensation due to nerve damage increases the risk of injury and makes wounds less noticeable because they do not hurt. Also, high blood sugar creates conditions favorable for bacteria and other microorganisms to proliferate, causing infection, while impaired blood flow to the legs and feet, as a result of peripheral arterial disease, impedes healing. The combination of these factors ultimately leads to amputation of the toes, feet, or legs.

Diabetes is also the leading cause of blindness among American adults. People with diabetes develop cataracts at an earlier age, are twice as likely to develop glaucoma, and are at risk for diabetic retinopathy, caused by swelling and blockage of the blood vessels that

46 Id.
47 See Powers, supra note 7, at 2428.
50 See Powers, supra note 7, at 2422, 2428.
51 Id. at 2424.
supply the retina at the back of the eye.\textsuperscript{52} All of these conditions typically develop slowly over time; in fact, many people do not even notice changes to their vision until their vision loss is irreversible. Management of diabetic retinopathy, which affects 40-45\% of diabetics to some degree, can require multiple laser surgeries to shrink abnormal blood vessels in the eye and reduce the amount of fluid in the retina.\textsuperscript{53}

The fact that most diabetes complications develop gradually after a long latency period, makes self-management of the disease all the more challenging. For some chronic conditions, such as congestive heart failure, if the patient deviates significantly from recommended dietary patterns, there is an immediate consequence, such as difficulty breathing.\textsuperscript{54} In sharp contrast, a person with diabetes can often get away with overconsumption of sugars and other carbohydrates for years without experiencing immediate complications.\textsuperscript{55} Blood sugar monitoring provides instantaneous feedback on the patient’s daily activities. However, the unpleasantness of receiving constant reminders that one is failing to follow guidelines may be one reason that many people with diabetes neglect to monitor their sugar as frequently as they should.

D. Social Disparities with Respect to Diabetes are Pervasive

People of color are far more likely to be diagnosed with diabetes than their non-Hispanic, white peers.\textsuperscript{56} Researchers estimate that more

\begin{itemize}
\item \textsuperscript{52} Facts About Diabetic Eye Disease, NAT’L EYE INST., https://nei.nih.gov/health/diabetic/retinopathy (last updated Sept. 2015).
\item \textsuperscript{53} Id.
\item \textsuperscript{54} See Heart Failure, UNIV. OF MO. MED. CTR., http://umm.edu/health/medical/altmed/condition/heart-failure (last visited July 18, 2016).
\item \textsuperscript{55} See PREVENTION OF TYPE 2 DIABETES 94–95 (Manfred Ganz ed., Wiley 2005).
\item \textsuperscript{56} When subpopulations are adjusted for age distribution, 7.6\% of non-Hispanic, white adults have been diagnosed with diabetes, while 9\% of Asian Americans, 12.8\% of Hispanics, 13.2\% of non-Hispanic blacks, and 15.9\% of American Indians/Alaska Natives have been. Of course, within these categories, there is significant variation. Among Hispanic adults, the age-adjusted rate of diagnosed diabetes varies from 8.5\% for people of Central and South American descent to 14.8\% for people of Puerto Rican descent. Among Asian Americans, it varied from 4.4\% (Chinese descent) to 13\% (East Indian descent). And among Native Americans/Alaska Natives, the rate varies from 6\% (Alaska natives) to more than 24\% (Native Americans in southern Arizona). NATIONAL DIABETES STATISTICS REPORT, supra note
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than 18% of all African Americans ages twenty and older have diabetes (diagnosed or undiagnosed), compared to about 7% of non-Hispanic, white Americans. People of color with diabetes are also more likely, than their white peers, to develop complications from diabetes, including lower limb amputations and end-stage renal disease. As one group of researchers put it, “the toll of this epidemic bludgeons racial and ethnic minorities.” The likelihood of being diagnosed with diabetes decreases with increased educational attainment and household income. Diabetes rates also vary considerably from county to county and from neighborhood to neighborhood.

Disparities across racial, ethnic, socioeconomic, and geographic lines indicate that social determinants play a powerful role in diabetes prevalence and management. Diabetes is influenced by

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9, at 2. The likelihood of having pre-diabetic blood sugar levels also varies by race and ethnicity, but not nearly as dramatically. 35% of non-Hispanic whites, 38% of Hispanics, and 39% of non-Hispanic blacks are estimated to be pre-diabetic. Id. at 3.


59 Chow et al., supra note 57, at 130.

60 According to the CDC, 14.3% of adults with less than a high school diploma, 11.1% of those with a high school diploma or GED, 10% of those with some college education, and only 6.2% of those with a bachelor’s degree or higher have diagnosed diabetes. SUMMARY HEALTH STATISTICS FOR U.S. ADULTS, supra note 58.

61 See id.


63 See, e.g., Rebecca S. Piccolo et al., The Role of Neighborhood Characteristics in Racial/Ethnic Disparities in Type 2 Diabetes: Results from the Boston Area Community Health (BACH) Survey, 130 SOC. SCI. & MED. 79, 86–87 (2015) (finding that diabetes rates vary considerably from neighborhood to neighborhood within the city of Boston).

64 See, e.g., SUMMARY HEALTH STATISTICS FOR U.S. ADULTS, supra note 58, at 31 tbl.8 (reporting that 1.4% of non-Hispanic whites had diagnosed kidney disease compared to 2.5% of non-Hispanic blacks, and 7.3% of non-Hispanic whites had diagnosed diabetes compared to 13.2%
“interdependent genetic, social, economic, cultural, and historic factors.” Social, economic, cultural, and geographic factors determine how affordable and convenient it is to eat a healthy diet. For example, one group of researchers found that only 18% of grocery stores in East Harlem stocked five recommended “diabetes-healthy choices” (defined by the researchers to include diet soda, one-percent or fat-free milk, high-fiber and low-carbohydrate bread, fresh fruits, and fresh green vegetables or tomatoes), compared to 50% of stores in the Upper East Side. The same factors determine how easy or difficult it is for a person to integrate physical activity into daily life. After adjusting for age, sex, family history of diabetes, income, and education, researchers found that the likelihood of insulin resistance decreases with increasing neighborhood resources for physical activity and healthy foods, while insulin resistance increases with increasing distance from the home to an area with good resources for physical activity and healthy food. The daily psychosocial stress that accompanies material deprivation, social stigma, and racial and ethnic discrimination affects daily choices about diet and physical activity, while also influencing blood sugar and other biometrics more directly. For example, the number and intensity of self-reported daily hassles occurring during the past week is positively associated with recent high blood glucose readings, even after adjusting for long-term blood sugar control. Also, the effects of material deprivation are pervasive and persistent. For example, childhood socioeconomic status is associated with type 2 diabetes and obesity later in life.

Compounding these injustices, people with diabetes face discrimination at school and work, and management of the disease

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65 Chow et al., supra note 57, at 130.
67 Amy H. Auchincloss et al., Neighborhood Resources of Physical Activity and Healthy Foods and Their Association with Insulin Resistance, 19 EPIDEMIOLOGY 146, 151 (2008).
68 J.E. Aikens & R. Mayes, Elevated Glycosylated Albumin in NIDDM is a Function of Recent, Everyday Environmental Stress, 20 DIABETES CARE 1111 (1997).
69 Teresa Tamayo et al., Impact of Early Psychosocial Factors (Childhood Socioeconomic Factors and Adversities) on Future Risk of Type 2 Diabetes, Metabolic Disturbances and Obesity: A Systematic Review, 10 BMC PUB. HEALTH 525, 525 (2010).
may interfere with educational and economic opportunities for them and their families.

II. THE LEGAL AND POLICY LANDSCAPE

There is widespread agreement among the public that diabetes and related chronic diseases warrant public attention and resources.\(^70\) The details of these measures, however, can be deeply divisive. Although there is widespread support for improving the quality of health insurance coverage for chronic disease management and preventive health care services, community prevention measures that aim to create healthier food retail environments and promote physically active modes of transportation continue to face opposition. Measures that put the onus on the individual to prevent and manage diabetes are often more politically palatable than those that regulate powerful industries or require significant public expenditure.\(^71\)

A. Prevention

Although pre-diabetes and diabetes are highly heritable, they are also heavily influenced by environmental triggers.\(^72\) Essentially, two people may have identical eating and activity patterns and one may develop diabetes while the other does not. Healthy eating and regular physical activity effectively prevent the progression from pre-diabetes to diabetes for many people, while also preventing complications and improving quality of life among those living with diabetes.\(^73\)

Pioneering state and local governments have adopted innovative regulations aimed at making communities more conducive to healthy

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70 Stephanie Morain & Michelle M. Mello, Survey Finds Public Support for Legal Interventions Directed at Health Behavior to Fight Noncommunicable Disease, 32 HEALTH AFF. 486, 489–90, 493 (2013) (finding high overall support for interventions to address noncommunicable disease, with the highest support for interventions that enable healthy choices, such as menu labeling and insurance coverage for nicotine patches, and lower support for coercive interventions such as insurance premium surcharges for those with high body mass index).


72 Emma Ahlqvist & Leif Groop, The Genetics of Type 2 Diabetes, in INTERNATIONAL TEXTBOOK OF DIABETES MELLITUS 550–63 (Ralph A. DeFronzo et al. eds., 4th ed. 2015).

73 See Look AHEAD Research Group, supra note 15.
eating. These interventions have included bans on trans-saturated fats in restaurant food, requirements that chain restaurants prominently display calorie counts on menu boards, zoning restrictions on new fast food outlets, and subsidies to promote the availability of healthier options. Several state and local governments either impose a special tax on sugar sweetened beverages or simply revoke the regular sales tax exemption that applies to other food and beverage sales when it comes to sugary drinks. But the tide appears to be turning against these measures, driven by “controversy over their effectiveness, their impact on the poor, general aversion to increased taxes,” as well as a well-financed lobbying campaign by the beverage industry. New sugary beverage tax proposals have largely been met


76 In 2008, Los Angeles City Council issued a one-year moratorium on the opening of any new fast food restaurants within a thirty-two mile radius. See Molly Hennessy-Fiske & David Zahniser, Council Bans New Fast-food Outlets, L.A. TIMES (July 30, 2008), http://articles.latimes.com/2008/jul/30/local/me-fastfood30. Also in California, Westwood Village’s zoning plan limits the establishment of new fast food restaurants within less than 400 feet of each other. See Paul A. Diller & Samantha Graff, Regulating Food Retail for Obesity: How Far Can Cities Go? 39 J.L. MED. & ETHICS 89, 92 (2011). Phoenix has banned mobile street vendors within 600 feet of schools during school hours. Id. Detroit similarly banned the opening of new fast food restaurants within 500 feet of schools. Id.

77 See Diller & Graff, supra note 76, at 89.


with political defeat,\textsuperscript{81} and some states have even repealed previously adopted taxes.\textsuperscript{82} A new federal tax on sugar-sweetened beverages was proposed as part of health reform efforts in 2009, but the proposal was dropped after fierce lobbying from the beverage industry.\textsuperscript{83} At the same time, federal regulators have continued to ignore commentators’ calls for restrictions on food and beverage advertising, deferring instead to industry self-regulation.\textsuperscript{84}

A few local governments have sought to regulate the configurations in which unhealthy food and beverage products may be sold. The healthy incentives ordinances—better known as the “Happy Meal ban”—adopted by Santa Clara County and the City of San Francisco in 2010, prohibit the inclusion of toys in children’s meals that contain unhealthy levels of calories, salt, or fat.\textsuperscript{85} This innovative intervention prompted an immediate political backlash from the food industry, which pushed for state legislation to preempt local authority over “all matters related to the nutritional content and marketing of foods offered” at food service establishments.\textsuperscript{86} The sugary drinks

\textsuperscript{81} See id. ("[D]uring the past two years, each of the 24 states and five cities that considered ‘soda taxes’ to discourage consumption of sugary drinks has seen the efforts dropped or defeated."); but see Caroline Scott-Thomas, D.C. Council Approves Soda Tax, FOOD NAVIGATOR-USA (May 28, 2010), http://www.foodnavigator-usa.com/Regulation/D.C.-Council-approves-soda-tax (noting that the Washington, D.C. Council approved a measure placing sweetened soft drinks in its 6% sales tax bracket in May of 2010).


portion rule—better known as the “Big Gulp ban”—adopted by the New York City Board of Health in 2012, would have prohibited the sale of sugar-sweetened beverages in cups larger than sixteen ounces. The measure provoked heated opposition and was ultimately struck down by the state supreme court on state administrative law grounds.

Many state and local governments are using legal and policy interventions to encourage increased physical activity. “Complete Streets” policies and development plans aimed at increasing the use of public transit to promote more active modes of transportation and integration of physical recreation into everyday life. But these measures typically require considerable public expenditure and may also increase costs for private developers. Several jurisdictions have also pioneered shared use agreements, whereby local agencies coordinate agreements to release schools, churches, and other entities from liability for personal injuries in exchange for opening up their recreational facilities to the public.

In the midst of controversy over local laws aimed at creating communities conducive to healthy eating and physical activity, the ACA included a new competitive program to fund Community Transformation Grants to fund “evidence-based community preventive health activities in order to reduce chronic disease rates.” More broadly, the ACA created a dedicated Prevention and Public Health Fund to support cross-sector and public-private partnerships.

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87 See N.Y.C. Dep’t of Health & Mental Hygiene, supra note 6, at 3.

88 See N.Y. Statewide Coal. of Hispanic Chambers of Commerce v. N.Y.C. Dep’t of Health & Mental Hygiene, 16 N.E.3d 538 (N.Y. 2014).


91 See generally John O. Spengler et al., Clarifying Liability for After-Hours Community Use of School Recreational Facilities, 22 ANNALS HEALTH L. 342 (2013) (exploring perceptions of after-hours liability risk for school administrators).

to promote public health and prevent chronic disease through screening, counseling, clinical care, and community-driven programs to reduce tobacco use, increase physical activity, improve nutrition, prevent injuries, and enhance mental health services.93

Additional ACA provisions, aimed at fostering private health insurance, employer, and Medicaid wellness programs, specifically target diabetes prevention and management, among other health risks. Wellness programs typically employ some combination of education, counseling, and financial incentives aimed at altering health behaviors. Public health researchers and advocates have argued in favor of workplace wellness programs that emphasize changes to the workplace environment—healthier food in the cafeteria, at meetings, and in vending machines, provision of an on-site gym, exercise classes, or shower facilities for those who bike to work.94 A few local governments have considered legislation promoting these kinds of environmental workplace policies.95 But the majority of large employers are eschewing environmental policies, which put the onus on the employer to offer a healthier worksite, in favor of behavioral policies, which put the onus on the employee to improve his or her own health.96 The ACA exempts wellness program incentives from its prohibition on risk-based underwriting, thereby allowing employers and insurers to alter the financial terms of coverage for employees who

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95 See, e.g., D.C. Council, B. 19-0143, 19th Sess. (D.C. 2011) (proposing the development of a workplace wellness policy for district government agencies to “expand opportunities for employees to store lunches and other healthy foods in District buildings[,]” encourage the provision of healthy foods by agencies, promote “the availability and consumption of water throughout the day,” and establish nutritional standards and calorie count labeling for items sold in vending machines under the control of the district).
decline to participate in behavior modification programs. The statute also provided for federal grants for states to develop Medicaid wellness programs.

B. Coverage

Insurance coverage affects the ability of individuals and families to manage diabetes. The medical care, medications, and supplies required to manage diabetes and its complications are expensive. Many patients underuse their medication because of cost concerns, and uninsured diabetics are less likely to receive recommended foot and eye exams. Diabetics who develop end-stage renal disease are eligible for Medicare coverage, but out-of-pocket expenses can be considerable—even for those who have coverage—and expenses rack up far short of the point at which a person with diabetes develops end-stage renal disease. Out-of-pocket expenses associated with diabetes are a significant contributor to bankruptcy, even for families that have insurance coverage.


98 42 U.S.C. § 1396a (establishing the Medicaid Incentives to Prevent Chronic Disease Program).

99 John D. Piette et al., Health Insurance Status, Cost-Related Medication Underuse, and Outcomes Among Diabetes Patients in Three Systems of Care, 42 Med. Care 102, 102 (2004) (finding that 9% of Veterans Administration patients report cost-related medication underuse, compared to 18% of patients with private insurance, 25% of those with Medicare (prior to implementation of drug prescription coverage), 31% of those with Medicaid, and that patients reporting cost-related underuse of medication had substantially higher A1c levels, more symptoms, and poorer physical and mental functioning).

100 See Karin M. Nelson et al., The Association Between Health Insurance Coverage and Diabetes Care, 40 Health Servs. Res. 361, 361 (2005).


102 David U. Himmelstein et al., Medical Bankruptcy in the United States, 2007: Results of a National Study, 122 Am. J. Med. 741, 744 (2009), http://www.amjmed.com/article/S0002-9343(09)00404-5/fulltext (finding that illness and/or medical bills contributed to 62.1% of all bankruptcies in 2007 and that, among those medically bankrupt families, out-of-pocket costs for diabetes (mean of $26,971) were exceeded only by those for non-stroke neurologic illnesses, such as multiple sclerosis).
ACA provisions expanding access to insurance coverage and consumer protections for those who are insured benefit people and families affected by chronic conditions like diabetes. The ACA required states to expand Medicaid eligibility to cover persons with incomes up to 138% of the federal poverty level, though this provision was made optional by the United States Supreme Court’s decision in **NFIB v. Sebelius**.\(^{103}\) State-based health insurance exchanges provide access to health insurance for individuals who cannot access affordable coverage as a benefit of employment and who are not eligible for Medicaid, Medicare, or the Children’s Health Insurance Program (“CHIP”) or are employed by small employers.\(^{104}\) Federal tax credits reduce premiums and cost sharing for low and middle-income individuals and families who purchase insurance on the exchanges.\(^{105}\) The law requires private insurers to allow young adults, up to age twenty-six, to remain on their parents’ health insurance.\(^{106}\) The law also provides for guaranteed issuance of insurance,\(^{107}\) ending denials of coverage for preexisting conditions, including diabetes. Individuals and families dealing with a new diabetes diagnosis benefit from the ACA’s prohibition on rescission, whereby an insurer revokes coverage after a patient incurs significant health care expenses.\(^{108}\) Those coping with significant diabetes complications, which can be quite costly, may benefit from the ACA’s prohibition on annual and lifetime limits on benefits.\(^{109}\)

Preventive health care services were a particular focus for the ACA’s drafters. Minimum benefit standards—called Essential Health Benefits—emphasize preventive care.\(^{110}\) The ACA also mandates that

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107 Id. § 300gg-1.
108 See id. § 300gg-12.
109 See id. § 300gg-11.
110 The ACA obligates private health plans offered on subsidized Health Insurance Exchanges, as well as privatized Medicaid “benchmark” plans to provide an Essential Health Benefit package, including the following ten categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use...
private health plans provide “first-dollar” coverage for preventive services that are recommended by the U.S. Preventive Services Task Force (“USPSTF”) and other specified groups. Privately insured individuals can obtain these services, including screening tests and counseling, without being subject to a deductible, co-payment, or co-insurance. In 2015, the USPSTF adopted a recommendation that adults aged forty to seventy, who are overweight or obese, be screened for abnormal blood glucose levels, and that those with abnormal levels be referred to intensive behavioral counseling interventions.

C. Care

As more Americans gain access to health insurance, the public’s interest in controlling the costs of care is increasing. Insured diabetics have greater access to health care and higher health care expenditures than those who are uninsured, but gaining access to coverage may not, by itself, improve health outcomes. Expanding access to health insurance may lead to better outcomes and lower expenditures in the long run, but only if health care services for diabetes are effective and efficient.

[Notes]

111 Id. § 300gg-13(a); See Group Health Plans and Health Insurance Issuers Relating to Coverage of Preventive Services Under the ACA, 76 Fed. Reg. 46,621, 46,626 (Aug. 3, 2011) (to be codified at 45 C.F.R. pt. 147) (announcing the interim final rule regarding coverage of preventive health services).


114 See Katherine Baicker et al., The Oregon Experiment—Effects of Medicaid on Clinical Outcomes, 368 NEW ENG. J. MED. 1713, 1718-20 (2013) (finding that Medicaid coverage increased the probability of a diagnosis of diabetes and the subsequent use of medication, but that it had no significant effect on the prevalence of measured glycated hemoglobin levels of 6.5% or higher).
Intensive management of blood glucose levels and early detection of complications are essential to preventing diabetes morbidity and mortality. But intensive diabetes care requires proactive, coordinated care by multidisciplinary teams of health professionals—a health care delivery model that traditional fee-for-service reimbursement structures have not supported.

Several ACA provisions are aimed at transforming health care delivery to promote higher quality, more cost-effective management of chronic diseases like diabetes. Indeed, as one group of researchers recently noted, “[c]aring for people with chronic illnesses provides a crucial test for health care reform.”115 Grant opportunities and reimbursement incentives support proactive diabetes care management by multidisciplinary teams. The Medicare Independence at Home Demonstration Program116 and Medicaid Health Homes for enrollees with chronic conditions117 specifically target diabetes care. More broadly, the Medicare Shared Savings Program, initiated by the ACA, offers financial incentives to Accountable Care Organizations (“ACOs”) “to foster change in patient care so as to accelerate progress toward a three-part aim: better care for individuals; better health for populations; and slower growth in costs through improvements in care.”118 The Shared Savings Program and other ACA reimbursement incentives aim to shift health care delivery models toward greater emphasis on team-based primary care in which all providers practice at the top of their licenses.

Pursuant to an ACA mandate, DHHS is enhancing diabetes surveillance and quality standards, with an emphasis on more accurate classification and collection of diabetes mortality data.119

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DHHS is also promoting licensing and certification for providers who care for people with diabetes.\textsuperscript{120}

New York City, in addition to pioneering several changes to how restaurant food and beverages are sold, has pioneered an effort to monitor blood sugar management for diabetics, with feedback reports sent to health care providers as well as patients themselves. Laboratories are required to report all hemoglobin A\textsubscript{1c} test results.\textsuperscript{121} From 2006 to 2013, health care providers received quarterly reports to health care facilities and providers with best practice recommendations and rosters of patients in their practice who are in poor glycemic control.\textsuperscript{122} The health department also mailed information on diabetes management and available resources to patients whose glycated hemoglobin levels indicated that their disease is poorly managed.\textsuperscript{123}

D. Non-discrimination

The Americans with Disabilities Act ("ADA"),\textsuperscript{124} Family and Medical Leave Act,\textsuperscript{125} and other federal, state, and local laws provide...
protections and support for individuals and families coping with diabetes. However, whether diabetes constitutes a disability for the purposes of an antidiscrimination law generally requires an individualized inquiry.126

In addition to prohibiting overt discrimination against people with disabilities, the ADA requires employers, public programs, and public accommodations to alter policies, practices, and physical environments where doing so represents a reasonable accommodation of the needs of people with disabilities.127 For example, the American Diabetes Association lists common reasonable accommodations for employees with diabetes, including:

- Breaks to check blood glucose levels, eat a snack, take medication, or go to the bathroom;
- A place to rest until blood sugar levels become normal;
- The ability to keep diabetes supplies and food nearby;
- The ability to test blood glucose and inject insulin anywhere at work;
- If requested, a private area to test blood glucose or administer insulin;
- Modifications to no-fault attendance policies;
- Leave for treatment, recuperation, or training on managing diabetes . . . ;
- The opportunity to work a modified work schedule or to work a standard shift as opposed to a swing shift;
- For individuals with diabetic neuropathy (a nerve disorder caused by diabetes), permission to use a chair or stool;
- For individuals with diabetic retinopathy (a vision disorder caused by diabetes), large screen computer monitors or other assistive devices.128

The Americans Diabetes Association also notes that public accommodations and government programs must allow people with diabetes to bring supplies, such as syringes, lancets, and insulin, through security checkpoints at airports and courthouses, and provide

126 See, e.g., Schneider v. Giant of Md., 389 Fed. Appx. 263 (4th Cir. 2010) (holding that plaintiff employee’s type 1 diabetes was not a disability within the meaning of the Americans with Disabilities Act, and therefore plaintiff’s requested accommodation was not reasonable, because it did not substantially limit a major life activity, even though it caused peripheral neuropathy, retinopathy, and chronic foot ulcers).


breaks to check blood sugar levels, take medication, eat, drink, and use the restroom.\textsuperscript{129}

In theory, ADA anti-discrimination provisions would constrain employer wellness programs that target employees with diabetes and other conditions that qualify as disabilities. For example, wellness programs routinely require screening tests to monitor body mass index, blood glucose, blood pressure, cholesterol, etc., but the ADA restricts employers’ authority to obtain medical information about employees.\textsuperscript{130} Two recent federal court decisions have held that wellness programs fall within a safe harbor for activities related to the administration of a bona fide insurance benefit plan,\textsuperscript{131} eroding significant protections for employees with diabetes and other disabilities.

III. REORIENTING THE HEALTH SYSTEM’S RESPONSE TO DIABETES

A. Health Justice as a Framework for Responding to Diabetes as a Social Phenomenon

In previous work, I have described health justice as an emerging framework for eliminating health disparities\textsuperscript{132} and for securing uniquely public interests in access to affordable, high-quality health care.\textsuperscript{133} Drawing on the experiences of the reproductive justice, environmental justice, and food justice movements, and on the writings of political philosophers and ethicists on health justice, I have


\textsuperscript{130} 42 U.S.C. § 12112(d)(4)(A) (“A covered entity shall not require a medical examination and shall not make inquiries of an employee as to whether such employee is an individual with a disability or as to the nature or severity of the disability, unless such examination or inquiry is shown to be job-related and consistent with business necessity.”).

\textsuperscript{131} Seff v. Broward Cty., 691 F.3d 1221, 1222 (11th Cir. 2012); EEOC v. Flambeau, 2015 WL 9593632 (W.D. Wis. 2015).

\textsuperscript{132} See, e.g., Wiley, supra note 22, at 47.

\textsuperscript{133} Securing Public Interest, supra note 22.
argued that the nascent health justice framework suggests three commitments for the use of law to reduce health disparities. First, to a broader inquiry that observes access to health care as one among many social determinants of health deserving of public attention and resources. Second, to a more probing inquiry into the effects of class, racial, and other forms of social and cultural bias on the design and implementation of measures to reduce health disparities. And third, to collective action grounded in community engagement and participatory parity. Here, I apply these three commitments to efforts to use law and policy to eliminate social disparities in the burden of diabetes. I argue that the transition from viewing diabetes primarily at the individual level, as a self-managed disease, to a community-managed social phenomenon is consistent with the health justice framework. In turn, continued law and policy reform along the lines of the health justice model can and should support this transition.

Racial, ethnic, and class bias certainly play a role in shaping political support for various responses to the diabetes epidemic. The health justice framework’s insistence on critical examination of interventions to reduce health disparities is thus highly relevant to diabetes. The heavy emphasis on patient education for diabetes prevention and management—aimed at urging individuals with (or at risk for) diabetes to make better choices without necessarily making it easier for them to do so—undermines the collective approach favored by the health justice model, while also reflecting biased views that people with (or at risk for) diabetes are to blame for their own condition.

The individualistic notion that diabetes is primarily a self-managed disease permeates legal and policy responses to the diabetes epidemic. Reimbursement incentives, to improve the quality of diabetes care, emphasize self-management education as a key benchmark. Interdisciplinary care management teams emphasize the availability of non-physicians to train patients to take a more active role in managing their own illness. Disability accommodations focus

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134 Wiley, supra note 132, at 87–95.
135 Id. at 95–101.
136 Id. at 101–04.
137 See Mensing et al., supra note 34.
exclusively on removing barriers to individual efforts to manage the disease. Opponents of regulation aimed at making our food system healthier and spending aimed at facilitating physical activity routinely argue that diabetes, obesity, and related health concerns are a matter of personal, not collective, responsibility. The not-so-subtle subtext is that people with diabetes have only themselves to blame.

In contrast, the health justice model emphasizes that social, economic, and environmental factors that operate at the population or community level in fact play a powerful role in shaping diabetes risk and health outcomes. Material deprivation, lack of social capital, and psychosocial stress influence diabetes risk at the individual, household, and neighborhood level. And the stress, depression, financial burdens, and interference with employment and other obligations associated with diabetes may further exacerbate health problems. The dramatic rise in diabetes prevalence over the last several decades is best understood as the product of social phenomena—a food system that produces excessive amounts of processed foods heavy in sugar, salt, and fat, and a built environment that discourages active modes of transportation and recreation—rather than the aggregated effect of millions upon millions of bad choices. Interventions like patient education and counseling that rely heavily on individual effort tend to have less population impact than those that focus on changing the environment to facilitate healthier choices.

As the newspaper article quoted in the epigraph at the beginning of this Article highlights, place plays a particularly important role in the diabetes epidemic. The communities where high-quality health care is least accessible tend to be the communities where opportunities


140 Id.


142 See supra note 1.
for safe and appealing physical recreation and transportation are lacking, and where healthy, convenient, affordable, and appealing foods are hard to come by. Racial and economic segregation create, perpetuate, and reify these health disparities. And, in turn, the pervasive and insidious impact of diabetes on communities presents a major barrier to racial and economic justice.

The ACA’s multi-faceted strategy for expanding access to health care will undoubtedly have benefits for diabetes management, but access to health care plays a relatively small role in health disparities. Following the health justice model, access to health care is one among many social determinants of health. Integration of health care and population health goals, strategies, and systems, preferably with health care subordinated to the broader umbrella of a comprehensive health system, is an important component of health justice. Thus, as I discuss in detail below, recent proposals to integrate health care with community-level prevention and management with respect to diabetes and obesity offer a potential path for operationalizing the health justice model.

B. Integrating Public Health and Health Care to Manage Diabetes at the Community Level

As described above, local, state and federal policymakers and advocates have pioneered innovative interventions to promote healthy eating and physical activity at the community level. Simultaneously, health care providers and third party payers are developing new health care delivery models to proactively manage diabetes care using multidisciplinary teams. But these efforts have not been integrated in any meaningful way. Individuals and families are encouraged to make healthier choices by government agencies, and patients with diabetes, obesity, and related chronic conditions are educated in self-management by health care providers. And while health care providers understand on some level that patients are also family members and community members, they can only do so much to achieve structural change.

143 See Securing Public Interest, supra note 22.
A proposal recently put forward by a diverse group of co-authors with medical, public health, legal, health policy, exercise physiology, and nutritional biochemistry expertise representing academic institutions, charitable foundations, community organizations, and health care providers suggests a possible strategy for applying the health justice framework to diabetes prevention and management. William H. Dietz and his co-authors propose an “integrated framework for the prevention and treatment of obesity and its related chronic diseases.” They adopt as a starting point the chronic care model, which has driven changes in the organization of the health care system with “patient self-management, or family self-management in the case of children . . . seen as the primary outcome.” They describe their proposal as a new iteration of the chronic care model, emphasizing full integration of clinical care and community systems for the prevention and management of obesity and related chronic diseases:

Restructured clinical services by providers who are sensitive to the stigmatization of patients with obesity and who use behavior change strategies to engage patients ... are more likely to help patients successfully change their diet, reduce inactivity, or increase physical activity. However, clinical efforts will not succeed without complementary community systems that make healthier choices the default or easier option. For example, patients cannot make healthful food choices without access to healthful food; nor can they become physically active without access to safe places for physical activity. Changes in both provider behavior and community systems are central

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144 William H. Dietz et al., An Integrated Framework for the Prevention and Treatment of Obesity and its Related Chronic Diseases, 34 HEALTH AFF. 1456, 1456 (2015) (authored by: William H. Dietz, M.D., Ph.D. (nutritional biochemistry), director of the Redstone Global Center for Prevention and Wellness at George Washington University; Loel S. Solomon, Ph.D. (health policy), vice president of community health at Kaiser Permanente in Oakland, California; Nico Pronk, Ph.D. (exercise physiology), vice president of health promotion at HealthPartners in Bloomington, Minnesota; Sarah K. Ziegenhorn, research associate at the National Academy of Medicine; Marion Standish, J.D., vice president of enterprise programs at the California Endowment; Matt M. Longjohn, M.D., M.P.H., national health officer at the YMCA of the USA; David D. Fukuzawa, M.Div., M.S. (administration), health program director at the Kresge Foundation; Ihuoma U. Eneli, M.D., medical director at the Center for Healthy Weight and Nutrition at Nationwide Children’s Hospital in Columbus, Ohio; and Lisel Loy, J.D., director of the Nutrition and Physical Activity Initiative at the Bipartisan Policy Center).

145 Id. at 1456.

146 Id. at 1457.
to success. From the clinical side, patient behavior change is the product of the provider-patient interaction. From the community-system side, population behavior change is a product of policies, initiatives, and interventions that change environments and social norms. One cannot succeed without the other.\textsuperscript{147}

Dietz et al. propose that “[c]ommunity health workers and community leaders, not typically considered health professionals, could play an important and sometimes leading role in effective integrated efforts to combat obesity and its related chronic diseases, such as type 2 diabetes mellitus.”\textsuperscript{148} They envision an integrated network whereby providers refer patients to community programs while also “advocating and strengthening community nutrition and physical activity resources that complement and reinforce clinical strategies.”\textsuperscript{149}

Dietz et al. point to several interrelated challenges: “Successful integration will require a trusted convenor or integrator, who commands mutual respect and shares stakeholder values.”\textsuperscript{150} Shared data systems are also essential to facilitate communication among health care providers, social service providers, and community organizations focused on ensuring access to healthy food and opportunities for physical activity.\textsuperscript{151} They envision integration as a private governance process led by private health care systems—organizations like Kaiser Permanente in Oakland, California and HealthPartners in Bloomington, Minnesota that encompass both health insurance products and health care delivery systems.\textsuperscript{152} They emphasize the need for private financing, which they suggest may be encouraged by new hospital community benefit requirements, new Medicare payment incentives, and corporate support for “workforce

\textsuperscript{147} Id.

\textsuperscript{148} Id.

\textsuperscript{149} Id.

\textsuperscript{150} Id. at 1459.

\textsuperscript{151} Id. at 1460.

\textsuperscript{152} The article does not specify that integration must be led by private health systems, but virtually all of the illustrations provided in the article describe local integration efforts led by integrated health systems such as HealthPartners in Minneapolis, Minnesota and Kaiser Permanente in Oakland, California, both of which are represented among the paper’s illustrious co-authors. Furthermore, the challenges identified in the article assume a private governance approach. Id. at 1459–62.
wellness. They point to the need for negotiation of private agreements among health care providers and community organizations. However, in focusing almost exclusively on private integrated health system-led integration, they overlook (or perhaps implicitly reject) the possibility of state or local government agency-led integration.

A 2011 article by Trajko Bojadzievski and Robert Gabbay, on the importance of patient-centered medical homes to diabetes management, could provide a model for an agency-led alternative to the Dietz proposal to integrate clinical services with community prevention and management efforts. Bojadzievski and Gabbay detail the efforts of Pennsylvania and Rhode Island to facilitate the development of patient-centered medical homes for diabetes care (a vehicle for adoption of the chronic care model that Dietz et al. take as their starting point). In Pennsylvania in 2008, the Governor’s Office for Health Care Reform (“GOHCR”) convened the major third party payers operating in the state, including Medicaid HMOs, to adopt incentives for statewide implementation of the patient-centered medical home model for treatment of diabetes. As of 2015, the program has supported more than 170 primary care practices, including a high preponderance of small practice groups in which the patient-centered medical home model has not been feasible) and has achieved improvements in blood sugar control and cholesterol, while also increasing the proportion of patients receiving recommended eye and foot exams. Because discussions among participating insurers and providers regarding payment are supervised by GOHCR, they are protected from antitrust enforcement, thus removing a potential

153 Id. at 1460–61.
154 Id. at 1462.
155 See Bojadzievski & Gabbay, supra note 26, at 1047.
156 See id. at 1047 (describing the patient-centered medical home as a vehicle for adoption of the chronic care model); Id. at 1049 (describing the Pennsylvania Chronic Care Initiative initiated by the Pennsylvania Governor’s Office for Health Care Reform and a similar, but smaller initiative convened by the Rhode Island Office of the Health Insurance Commissioner).
157 Dietz et al., supra note 144, at 1462.
barrier to integration. GOHCR also provides financial support to cover infrastructure improvements and certification costs, training programs and expert consultation for participating providers and payers, and multiple conduits for data sharing among and between providers and the agency. In Rhode Island, a similar initiative on a smaller scale was convened by the state Office of the Health Insurance Commissioner.

State agencies could remove similar legal barriers that stand in the way of integrating proactive diabetes care management with community prevention and management. Whereas the Dietz proposal gives the integrator role to the clinical side, thus bringing public health and community prevention under the health care umbrella. My approach would give the integrator role to the community side, bringing health care and clinical prevention under the public health umbrella. The New York City A1c Registry provides a partial model for such an approach, with a health agency playing the role of data aggregator and connecting patients and providers to community resources.

There are multiple advantages to an agency-led approach to integrating clinical care and public health. Agencies have greater authority (and this authority could be further expanded by legislative bodies) to remove legal barriers to economic and data integration than private actors relying upon contractual agreements. The public health mindset adopted by many state and local agencies is more conducive to approaching diabetes as a social-ecological phenomenon, whereas the health care sector is only beginning to expand beyond a narrow focus on individualistic biomedical and behavioral approaches. Government agencies are also better situated than private health care providers and payers to pursue long-term benefits in exchange for short-term investments. And because the benefits of effective diabetes

159 Bojadzievski & Gabbay, supra note 26, at 1049.
160 Id.
161 Id.
162 Dietz et al., supra note 144, at 1456.
163 See supra text at notes 121–23.
management typically do not accrue for a decade or more, investments must be undertaken with a long-range view.

There are challenges, of course. State and local agencies are chronically underfunded. The Prevention and Public Health Fund established by the ACA represents an unprecedented investment in public health, but the funding is still inadequate to the task and the Fund remains politically vulnerable. As Dietz et al. note, the integrator must have the trust of health care and community stakeholders to perform its role effectively. I would add that the trust of the general public is also crucial to effective integration. The efforts of pioneering local health agencies, such as the New York Department of Health and Mental Hygiene and its Board of Health, to take on a more active role in preventing and managing chronic disease at the population level have been controversial to say the least. Integrated health care systems are a financially and politically powerful force and they would almost certainly prefer to lead the process of integration, as Dietz and his coauthors envision, than cede this function to state and local regulatory agencies. I would argue, however, that the authority to oversee health care and public health systems is inherent in state and local health agencies. It is theirs to cede to private integrated health systems, not the other way around.

164 See Judith E. Fradkin, Confronting the Urgent Challenge of Diabetes: An Overview, 31 HEALTH AFF. 12, 17 (2012) (“The disease and its complications develop over decades . . . . Reductions in cardiovascular disease, for example, did not emerge until a decade after the completion of trials of glucose control in type 1 and type 2 diabetes. Demonstration of reduced risk of impaired kidney function in type 1 diabetes required two decades of follow-up. However, nearly two decades after the Diabetes Control and Complications Trial ended, investigators continue to observe a reduced incidence of diabetes complications in participants . . . . Thus, the benefits of effective therapy to prevent type 2 diabetes or its complications are likely to grow over a longer period than the ten-year time frame used by the Congressional Budget Office to score costs and savings . . . . For all of these reasons, effective therapy may entail upfront costs with savings realized decades later.”).

165 Dietz et al., supra note 144, at 1459.

166 See generally Shadi Chamany et al., Tracking Diabetes: New York City’s A1C Registry, 87 MILBANK Q. 548 (2009) (discussing the rationale for required A1c testing and reporting in New York City, and the criticism and controversy that it created).
CONCLUSION: RESPONDING TO THE MUTUAL VULNERABILITIES EXPOSED BY DIABETES AS A COMMUNITY-MANAGED SOCIAL PHENOMENON

In this Article, I have sketched out one approach to managing diabetes at the community level by integrating public health and health care strategies. Doing more to connect individuals and families with community resources and integrate community services with clinical services are sensible starting points. But the growing impact of diabetes in the United States also demands that we increase and enhance community services, regulate commercial activity to facilitate healthy eating and physical activity, and build social capital at the community level. This is ultimately one small part of a much larger project.

Examining the current legal landscape for diabetes prevention and management through a health justice lens reveals the injustice of policies that privilege biomedical and behavioral models and the extent to which racial, economic, and health justice are intertwined. Just as the U.S. is moving toward a more collective approach to financing clinical care, we must also move toward a more collective approach to preventing and managing chronic disease in communities. Public accommodations, employers, and public programs are currently required by disability discrimination laws to remove barriers that might otherwise prevent people with diabetes from keeping necessary medical supplies close at hand. But, what if we could take the accommodation model further? Not necessarily in response to antidiscrimination law, but as a matter of health policy, communities could be doing so much more to accommodate and facilitate the healthy eating and physical activity needs of people with diabetes and pre-diabetes, and indeed of families and individuals generally. A collective, mutual-aid, justice-oriented approach to health law and policy is only just beginning to emerge in the U.S. Its potential for transforming our health system and our social and cultural understandings of the relationships between health and society is vast, but it will also face many challenges from the politically and financially powerful stakeholders—in the health care industry, the food and beverage industry, and beyond—who benefit from a more narrow view of collective responsibility for health.