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Working Sick: Lessons of Chronic Illness for Health Care Reform

Elizabeth Pendo

INTRODUCTION

Although chronic illness is generally associated with the elderly or disabled, chronic conditions are widespread among working-age adults and pose significant challenges for employer-based health care plans. Indeed, a recent study found that the number of working-age adults with a major chronic condition has grown by 25% over the past ten years, to a total of nearly 58 million in 2006. Chronic illness imposes significant costs on workers, employers, and the overall economy. This population accounts for three-quarters of all health care expenditures in the United States, and a Milken Institute study recently estimated that lost workdays and lower productivity as a result of the seven most common chronic diseases results in an annual loss of over $1 trillion dollars.

* Professor of Law, Saint Louis University School of Law, Center for Health Law Studies; B.A. 1990, University of California, Los Angeles; J.D. 1993, UC Berkeley Boalt Hall School of Law. Thank you to my co-panelists and to the Section on Employee Benefits for the invitation to contribute to the panel, “The Role of Employers in Achieving Universal Health Care Coverage.” at the 2009 AALS Annual Meeting. Thank you also Stacy Connelly for excellent research assistance.

1. Chronic illness is generally defined as a condition, impairment or disease that lasts three or more months and creates ongoing health consequences, the need for ongoing medical care, or both. See, e.g., Catherine Hoffman, Dorothy Rice & Hai-Yen Sung, Persons with Chronic Conditions: Their Prevalence and Costs, 276 JAMA 1473 (1996) (citing the National Medical Expenditures Survey definition of chronic condition, which includes a disease, symptoms, or impairment lasting years, not months or days); Kathryn Anne Paez, Lan Zhao & Wenke Hwang, Rising Out-of-Pocket Spending for Chronic Conditions: A Ten-Year Trend, HEALTH AFF., Jan.-Feb. 2009, at 16 (defining chronic conditions as those that “had lasted or [were] expected to last twelve or more months and result in functional limitation and/or the need for ongoing medical care”). Of course, many of the considerations discussed in this Article also apply to workers with a chronically ill family member.


3. Hoffman et al., supra note 1, at 1477 fig.1.

I am focusing on this significant and growing population as a challenge for employers and as a critical test case for current health care reform proposals. Many of the cost-control methods used by employer-based plans simply shift rather than lower health care costs. This disproportionately burdens people with chronic illnesses and creates long-term social and economic costs. The experiences and challenges of workers with chronic illness provide an opportunity to examine the larger framework of health care reform, not just the employer’s role in isolation, and they make clear that chronic illness is an issue that must be addressed by employers and policymakers.

I. CHRONIC ILLNESS IN THE WORKPLACE

Scholars have paid surprisingly little attention to chronic illness in the workplace.5 One of the first studies to assess the prevalence of chronic illness, published in the Journal of the American Medical Association (JAMA) in 1996, found that that over 45% of non-institutionalized Americans, or 90 million people, were living with one or more chronic condition.6 The study also found that the health care costs for this population were disproportionately high, accounting for three-quarters of U.S. health care expenditures.7

Two studies that focused on the working-age population found that chronic illnesses affected more than a third of working-age Americans in 1999.8 A more recent and comprehensive study, published in 2008, found that more than 40% of the population lives with one or more chronic conditions; 60% of them, about 65 million people, are working-age adults.9 The majority of people defined by this study to have chronic illnesses were not “disabled.” Only 2% reported having problems with activities of daily living, although many did report some work limitations.10 Significantly, this study also found that the number of working-age

5. See Hoffman et al., supra note 1, at 1474 (noting that the prevalence and costs of chronic conditions as a whole have rarely been estimated.).
6. Id. at 1475-76.
7. Id. at 1476.
9. Hoffman & Schwartz, supra note 2. at w340; see also Paez et al., supra note 1, at 17 (reporting that 43.8% of civilian, non-institutionalized Americans had one or more chronic conditions).
10. This was also noted in the 1996 study. Hoffman et al., supra note 1. Several definitions of disability could be relevant. The Social Security Administration defines “disability” as the “inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be
adults with a major chronic condition has grown 25% over ten years, and the percentage has increased from 28% in 1997 to 31% by 2006.\footnote{11}

Scholars offer several reasons for the increased prevalence of chronic illness, including the aging population.\footnote{12} Factors that relate to the increased prevalence of chronic illness among the working-age population include rising rates of risk factors such as obesity and advances in medical treatment that have converted once-fatal conditions to manageable chronic conditions.\footnote{13}

The majority of this significant and growing population of 65 million is able to work, suggesting that millions of people may be working with chronic illness, and participating in employer-based health care plans. Indeed, the studies referenced above\footnote{14} found that people with chronic conditions were more likely to be insured than people without chronic conditions, and 71% of working-age adults with chronic conditions were covered by private insurance, including employer-based plans.\footnote{15}

Although employer-based coverage has its critics,\footnote{16} the experiences of the expected to last for a continuous period of not less than twelve months’ employment.” 42 U.S.C. § 416(i)(1)(A) (2000). An employer’s long-term disability plan typically defines “disability” as an inability to perform the material duties of your own occupation or as the inability to perform any occupation for which you are is suited by education, training, or experience. See Elizabeth Pendo, Disability, Doctors and Dollars: Distinguishing the Three Faces of Reasonable Accommodation, 35 U.C. DAVIS L. REV. 1175 (2002) (discussing these definitions and collecting cases). Finally, the Americans with Disabilities Act defines “disability” to mean, with respect to any individual: 1) a physical or mental impairment that substantially limits one or more major life activities; 2) a record of such impairment; or 3) being regarded as having such an impairment regardless of whether the individual actually has the impairment. 42 U.S.C.A. § 12102(1) (2000).

\footnote{11} Hoffman & Schwartz, supra note 2, at w342.

\footnote{12} See, e.g., Thomas Bodenheimer et al., Confronting the Growing Burden of Chronic Disease: Can the U.S. Health Care Workforce Do the Job?, HEALTH AFF., Jan.-Feb. 2009, at 64, 65 (describing America’s aging population and the rise in obesity among this group); Edward H. Wagner et al., Improving Chronic Illness Care: Translating Evidence into Action, HEALTH AFF., Nov.-Dec. 2001, at 64 (discussing rapid aging of the population and increased longevity of people with chronic conditions).

\footnote{13} See, e.g., Aviva Must et al., The Disease Burden Associated with Overweight and Obesity, 282 JAMA 1523 (1999) (noting the association of obesity with heart disease, diabetes, stroke, arthritis, and some forms of cancer); Kenneth R. Thorpe, Differences in Disease Prevalence as a Source of the U.S.-European Health Care Spending Gap, HEALTH AFF., Oct. 2. 2007, at w678, w684 (web exclusive) (“A voluminous literature exists highlighting the association between obesity, smoking, and several chronic conditions.”).

\footnote{14} See REED & TU, supra note 8.

\footnote{15} Id. at 1.

\footnote{16} See, e.g., David A. Hyman & Mark Hall, Two Cheers for Employment-Based Health Insurance, 2 YALE J. HEALTH POL’Y L. & ETHICS 23 (2001) (discussing the costs and benefits of the employer-based system).
chronically ill who are both working and insured highlight the advantages of employer-based coverage—at least relative to other currently-available options—since workers with chronic illness enjoy some federally-mandated protections. For example, employer-based plans can not deny or discriminate on the basis of health history, nor can they exclude pre-existing conditions from coverage.\(^{17}\) For the same reasons, workers with chronic illness may also suffer the disadvantages of employer-based coverage, including labor market distortions such as job lock.\(^{18}\)

It is well established that chronic illness accounts for a disproportionate share of health care costs. As stated above, the 1996 \textit{JAMA} article contains the oft-quoted finding that health care costs for the chronically ill account for three-quarters of U.S. health care expenditures, and other studies have made similar findings.\(^{19}\) In fact, one later study found that the treatment of one or more of just five chronic conditions accounted for $62.3 billion in health care costs in 1996—almost half of the total U.S. health care spending for that year.\(^{20}\)

\section*{II. The Meaning of "Controlling Costs"}

Despite the erosion of employer-based coverage, it is still true that most Americans get their health insurance through employment.\(^{21}\) Although no one can predict with certainty, it appears that employer-based coverage is here to stay, at least for a while. The leading Democratic proposals for health care reform, discussed below in Part IV, include efforts to maintain or strengthen the employer-based system and envision that people who have coverage through their employer or otherwise would be permitted to keep that coverage.\(^{22}\) The

\begin{itemize}
\item \(18\) Kevin T. Stroupe, Eleanor D. Kinney & Thomas J.J. Kniesner, \textit{Chronic Illness and Health Insurance-Related Job Lock}, 20 J. POL’Y ANALYSIS & MGMT. 525 (2001) (finding that job lock is substantial among workers with a chronic illness).
\item \(19\) See, \textit{e.g.}, ROBERT L. MOLLLICA & JENNIFER GILLISPE, NAT’L ACAD. FOR STATE HEALTH POLICY, CARE COORDINATION FOR PEOPLE WITH CHRONIC CONDITIONS 3 (2003) (noting that care for people with chronic illness consumes 78% of all health care spending); Centers for Disease Control and Prevention, Chronic Disease Overview, http://www.cdc.gov/NCCdphp/overview.htm.
\item \(20\) Benjamin G. Druss et al., \textit{Comparing the National Economic Burden of Five Chronic Conditions}, HEALTH AFF., NOV.-DEC. 2001, at 233.
\item \(21\) \textit{The Henry J. Kaiser Family Found., Employer Health Benefits 2008 Annual Survey} 46 (2008) (finding that 60% of workers and 158 million people are covered by employer-based plans).
continuing role of employers as sponsors of health insurance plans for millions of chronically ill employees and their families places them in a key position to influence developments in health care policy.

Clearly, a major challenge facing employers is the increasing cost of providing health insurance benefits. A recent survey found that 54.2% of employers identified controlling costs as their highest health care priority, and they do recognize workers with chronic illness as a significant cost factor. In a recent survey, over 56% of responding employers identified chronic health conditions as a top source of health care costs, topped only by the aging population at 58%. Employers turned to managed care to control costs in the 1990s, but they retreated in the face of a backlash against its most restrictive practices. More recently, employers have turned toward consumer-driven health plans. Nonetheless, costs continue to rise beyond the means of many employers.

Of course, “controlling costs” has more than one meaning. Often, it means limiting the share of the cost borne by employers by pushing a greater share of the costs to employees. This can mean requiring them to pay a higher percentage of the premium or imposing cost-sharing measures such as higher deductibles, co-insurance, and co-payments.

Increased cost-sharing is bad for the chronically ill because they require a higher level of health care services. For this reason, even when they are insured, people with chronic conditions spend more out-of-pocket than do people without chronic conditions. One study found that having one chronic condition


23. Most Employers Favor Health System Reform that Keeps Job-Based System, Survey Shows, BNA DAILY HEALTH CARE REPORT (Bureau of Nat’l Affairs), Nov. 17, 2008 (on file with author).


increases it by more than 70%, and having two conditions increases it by 300%. There is also evidence that the out-of-pocket spending of the chronically ill is increasing over time: by nearly 40% in less than ten years according to one estimate. If it is true that chronic illnesses are increasingly treated with prescription drugs and in outpatient settings, cost-sharing will be even more detrimental to the chronically ill.

At some point, cost becomes prohibitive for everybody; insured people with chronic conditions report going without needed medical care due to cost. Indeed, “[t]he evidence is overwhelming that cost-sharing reduces the use of medically effective care.” Increased cost-sharing disproportionately impacts people with chronic illness, causing long-term health consequences and potentially increased health care costs. Deborah Stone neatly illustrates this point with reference to prescription drugs:

Cost-sharing for prescription drugs lowers adherence to drug regimens. It leads people to refill prescriptions sporadically only when they can afford the co-payment, and sometimes to discontinue drugs altogether. For patients with some serious chronic illnesses such as congestive heart failure, diabetes, and schizophrenia, higher cost-sharing for prescription drugs is associated with greater use of medical services.

Pushing additional costs onto the chronically ill might help employers control costs in the short term but it may also increase costs in the long term and it hinders efforts to spread risk and subsidize losses across the insured population.

This point is not lost on employers, who are concerned that employees who forgo needed medical care “could end up costing . . . more later in both additional health care expenditures and increased absenteeism should a serious health threat go untreated or a chronic condition get worse.”

27. Hoffman & Schwartz, supra note 2, at w346.
28. Paez et al., supra note 1, at 22 (noting that “[p]eople using health services spent an average of $741 in 2005 for health care services,” a 39.4% increase from 1996 when adjusted for inflation).
29. Sandra L. Decker et al., Use of Medical Care for Chronic Conditions, Health Aff. Jan.-Feb. 2009, at 26 (reporting that delivery of care for chronic conditions is shifting from inpatient to ambulatory setting); Paez et al., supra note 1, at 20 (summarizing research on increased use of medications).
30. Hoffman and Schwartz, supra note 2, at w345.
31. Stone, supra note 25, at 655.
32. See Paez et al., supra note 1.
33. Stone, supra note 25, at 656; see also SARA R. COLLINS ET AL., THE COMMONWEALTH FUND, GAPS IN HEALTH INSURANCE: AN ALL-AMERICAN PROBLEM 9 (2006) (reporting that 59% of uninsured adults with a chronic condition such as diabetes and asthma did not fill a prescription or skipped medications due to cost).
relating to chronic illness in terms of productivity; although estimates of these
costs vary tremendously—from $75 billion to $1 trillion annually—everybody
recognizes that they are enormous. 35

If “controlling costs” can refer to an employer’s strategy to shift a greater
share of the costs to employees, it can also refer to an employer’s efforts to lower
the overall cost of health care, not just its own share. Via their funding of health-
promotion and wellness programs, some employers are emphasizing long-term
cost-effectiveness rather than just short-term costs-savings. 36 However, it is not
yet clear whether these programs achieve long-term cost-effectiveness. In
addition, as Wendy Mariner has written, wellness programs may effectively raise
premiums for people with risk factors such as obesity, smoking, or diabetes by
giving “discounts” to people without these risk factors. 37 To the extent that these
programs increase the cost of health care for people with high health care needs,
they raise some of the same concerns as increased cost-sharing in terms of
detrimentally affecting the chronically ill. 38

III. LESSONS FOR EMPLOYERS AND REFORMERS

The rising incidence and prevalence of chronic illness in the workplace
leaves employers in a difficult position: although they need to control escalating
costs, they recognize the problems designing and implementing cost-saving
measures. Thus, the experiences and challenges of chronic illness in the
workplace provide an opportunity to examine the larger puzzle of national health
care reform. Indeed, the economic and social burdens created by chronic illness
reveal the need to look for systemic solutions rather than isolated fixes.

A proposal that addresses the employment-based system in isolation, for
example, fails to address the fact that employer-sponsored coverage is eroding

35. Opportunities Lost and Costs to Society: The Social and Economic Burden of Disease,
Injuries, and Disability: Hearing Before the Subcomm. on the Dep’t of Labor, Health and Human
(statement of Kenneth E. Thorpe) [hereinafter Thorpe Statement]; PAUL FRONSTIN & RAY WERNTZ,
THE “BUSINESS CASE” FOR INVESTING IN EMPLOYEE HEALTH: A REVIEW OF THE LITERATURE AND
EMPLOYER SELF-ASSESSMENTS (Employee Benefit Research Inst., Issue Brief No. 267, 2004).
PROGRESS, OPPORTUNITY COSTS AND OPPORTUNITIES LOST: BUSINESSES SPEAK OUT ABOUT THE

36. See Ron Z. Goetzel, Do Prevention or Treatment Services Save Money? The Wrong
Debate, HEALTH AFF., Jan.-Feb. 2009, at 37 (discussing studies of employer health promotion
programs).

37. Wendy K. Mariner, Social Solidarity and Personal Responsibility in Health Reform, 14

38. See Stone, supra note 25.
and becoming increasingly unstable for many workers. As unemployment figures climb, millions of workers face losing their coverage along with their jobs. There are, of course, some legal protections against such double jeopardy. In some cases, recently unemployed workers can continue group coverage under the Consolidated Omnibus Reconciliation Act of 1985 (COBRA), and then secure an offer of individual coverage under the Health Insurance Portability and Accessibility Act (HIPAA).  But COBRA is expensive: a recent study found that although most unemployed workers are eligible, fewer than one in ten extends coverage under this option. In recognition of this, the recent stimulus bill included premium subsidies and extended COBRA coverage periods for some of the recently unemployed.

There have also been some reports of “health discrimination,” a practice by which employers find reasons to fire or avoid hiring employees with expensive or chronic illnesses. Although the extent of this practice is unclear, its illegality is not. The Employee Retirement Income Security Act (ERISA) prohibits an employer from terminating an employee for the purpose of interfering with the worker’s protected rights to benefits such as participation in health insurance plans. There are also some important but limited protections for sick or disabled workers under the Americans with Disabilities Act and the Family and Medical Leave Act.

Notwithstanding these protections, workers are right to be concerned about

39. Under COBRA, recently unemployed workers may be eligible to extend their health insurance coverage for eighteen months at the group rate, and this coverage cannot be denied on the basis of health history. 29 U.S.C. § 1162(4) (2000). However, cost is often prohibitive, as the worker would be responsible for the entire premium plus administrative costs. Id. § 1162(3). Once the COBRA extension period is exhausted, HIPAA provides for conversion of group coverage into a renewable individual policy without exclusion for pre-existing conditions. Id. § 300gg-42. However, cost could be prohibitive under this option, as well, as HIPAA does not limit the premium that the offering insurer may charge. 42 U.S.C. § 300gg-41(f)(1) (2000).


43. See 29 U.S.C. § 1140 (2000). This does not, however, prevent an employer from amending the plan to change benefits generally. See McGann v. H & H Music Co., 946 F.2d 401 (5th Cir. 1991).

maintaining their coverage after losing their job: individual insurance policies are difficult to find and harder to afford. Without access to group coverage or a public program, workers with chronic illness are unlikely to get individual coverage at any price. Absent state law to the contrary, health insurers in the individual market are not required to offer or provide coverage. 45 In an unregulated market, insurers can exclude or impose waiting periods for coverage of pre-existing conditions, including chronic illnesses. 46 The Kaiser Family Foundation studied the efforts that seven hypothetically ill individuals would have to make to find health insurance. The applicants—of varying age, gender, and life circumstances and with seven different pre-existing conditions (hay fever, a surgically repaired knee, asthma and recurrent ear infections, breast cancer, depression, high blood pressure, and HIV-positive status)—were rejected 37% of the time. 47 Only 10% of the offers that were made were at the standard rate and most of them contained benefit restrictions, surcharges, or both. 48 In the unregulated individual market, people with chronic illness are offered coverage at prohibitively high rates or denied coverage all together. 49 A more recent study by the Commonwealth Fund reported that one in five applicants for an individual policy were declined, charged higher rates due to a pre-existing condition, or offered a policy with significant exclusions. 50


46. Id. at 10. As of 2000, thirty-one states had enacted laws limiting exclusions for pre-existing conditions. Id. at 7 fig.6.


48. Id. The average annual premium offered was $3,996, a significant increase from the standard average annual rate of $2,988. Id. at iii.


Without access to group coverage or a public program, most people with chronic illness would find themselves without insurance.\(^51\) And that means that their health would deteriorate further; it is well documented that people without insurance receive less care, receive delayed care, and suffer worse outcomes than people with insurance.\(^52\) Similar or worse disparities seem to exist for the uninsured with chronic illness.\(^53\) For example, recent studies have reported that people with chronic illness and without insurance were twice as likely as those with insurance to delay or forgo needed care, including basic preventative care,\(^54\) and were four to six times more likely to experience access problems.\(^55\) In addition to the detrimental health consequences, lack of insurance can bring financial ruin, and medical debt has a devastating effect on many families.\(^56\) So it is no surprise that people are working sick, scared, or both in order to retain much needed health insurance, and that stories of workers facing such choices have begun to appear in the news.\(^57\)

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51. According to a study published in 2008, 13% of working-age adults with chronic conditions were uninsured in 2006. Hoffman & Schwartz, supra note 2, at w342; see also Collins et al., supra note 50, at 19 tbl.1 (finding that 22% of full-time workers and 34% of part-time workers who were in fair or poor health, with any chronic condition or with a disability were uninsured for all or part of 2005); Reed & Tu, supra note 8, at 1 (finding that 12% of working-age adults with chronic conditions were uninsured in 1999).


53. See Reed & Tu, supra note 8, at 3.

54. See, e.g., Hoffman & Schwartz, supra note 2, at w345; see also Jack Hadley. Insurance Coverage, Medical Care Use and Short-Term Health Changes Following an Unintentional Injury or the Onset of a Chronic Condition, 297 JAMA 1073, 1074 (2007) ("Among individuals who experienced a health shock caused by an unintentional injury or a new chronic condition, uninsured individuals reported receiving less medical care and poorer short-term changes in health than those with insurance."); Andrew P. Wilper et al., A National Study of Chronic Disease Prevalence and Access to Care in Uninsured U.S. Adults, 149 Annals Internal Med. 170, 170 (2008) (reporting that people with chronic illness and without insurance were much less likely to have a usual source of care or to have seen a doctor in the past year, and much more likely to use the emergency room than the insured chronically ill).

55. See Wilper et al., supra note 54, at 174.

56. See, e.g., David U. Himmelstein et al., Illness and Injury as Contributors to Bankruptcy, Health Aff., Feb. 2, 2005, at w5-63, http://content.healthaffairs.org/cgi/content/abstract/healthaff.w5.63v1 (web exclusive); Robert W. Seifert & Mark Rukavina, Bankruptcy Is the Tip of a Medical-Debt Iceberg, Health Aff., Feb. 28, 2006, at w89, http://content.healthaffairs.org/cgi/content/full/25/2/w89 (web exclusive).

Consideration of the chronically ill also reminds us to look at the costs of chronic illness borne by public programs such as Medicare and Medicaid. Although in 2002 the majority of working-age people with chronic illness were covered by private insurance such as employer-based plans, 14% were covered by Medicare, Medicaid, or both.\textsuperscript{58} By some reports, ninety-six cents of every Medicare dollar and eighty-three cents of every Medicaid dollar are used to treat chronic diseases.\textsuperscript{59} There is also evidence that the employer-based system interacts with public programs, as some employers push the cost of providing coverage to their workers onto public programs,\textsuperscript{60} and public programs create additional costs for private plans.\textsuperscript{61}

IV. CHRONIC ILLNESS AND PROPOSALS FOR COMPREHENSIVE REFORM

Health care reform is at the top of the national agenda. It played a prominent role in the 2008 presidential election, and several members of Congress introduced bills during the 110th session aimed at health care reform.\textsuperscript{62} The burdens of chronic illness on workers, employers, and others reveal deep fault lines in our current system and the need to look for comprehensive solutions rather than isolated fixes. How might the lessons presented by the growing ranks of workers with chronic illness be applied to these health care reform efforts?

One influential proposal is the policy paper issued by Senate Finance Committee Chairman Max Baucus, in November 2008, outlining a plan to

\textsuperscript{58} Reed & Tu, supra note 8, at 1.
\textsuperscript{59} Thorne Statement, supra note 35, at 1.
\textsuperscript{60} See, e.g., Retail Indus. Leaders Ass’n v. Fielder, 475 F.3d 180, 183-84 (4th Cir. 2007) (noting testimony in legislative record regarding participation of children of Wal-Mart employees in the Medicaid and SCHIP programs in several states); Reed Abelson, States Are Battling Against Wal-Mart Over Health Care, N.Y. Times, Nov. 1, 2004, at A1; Ralph Thomas, Over 3,100 Wal-Mart Workers Got State Health Aid, SEATTLE TIMES, Jan. 24, 2006, at A1.
\textsuperscript{61} According to a recent study by Milliman, Inc., commercial payers subsidize Medicare and Medicaid by $88.8 billion annually by paying relatively higher rates. WILL FOX & JOHN PICKERING, MILLIMAN, INC., HOSPITAL AND PHYSICIAN COST SHIFT: PAYMENT LEVEL COMPARISON OF MEDICARE, MEDICAID, AND COMMERCIAL PAYERS 4 chart 4 (2008) (estimating that employers pay an additional $1115 and participants pay an additional $397 in premiums).
\textsuperscript{62} For a review of these Bills, see SARA R. COLLINS, JENNIFER L. NICHOLSON & SHEILA D. RUSTGI, THE COMMONWEALTH FUND, AN ANALYSIS OF LEADING CONGRESSIONAL HEALTH CARE BILLS, 2007-2008: PART I, INSURANCE COVERAGE (2009).
address health care coverage, quality, and cost. His proposal is intended to summarize points of consensus—at least among Democrats—and to create a place from which discussions about health care reform can start. The plan has three prongs: increasing access to affordable coverage for all Americans, improving the delivery system to increase value, and reforming health care financing to eliminate waste and promote efficiency. Not surprisingly, the Baucus Plan emphasizes shared responsibility, and employers are central players in his vision:

Employers, individuals, and government all have a role to play—and a contribution to make—to the system. Employers should contribute toward health insurance choices and financing. Individuals have the responsibility to get coverage, to take better care of their own health, and to play a larger role in health care treatment decisions. Providers should improve their performance to ensure consistent, high-quality health care. Society, through state and Federal governments, should help those who lack the means to buy insurance on their own and ensure that the insurance market is fair and transparent.

The Baucus Plan shares key similarities with the plan outlined by President Obama during his campaign and also with the proposal put forth by the Commonwealth Fund in May 2008, referred to as the “Building Blocks” framework, in that all propose comprehensive reform, including expansion of coverage through a mix of public and private group insurance options offered through a national exchange. Significantly, all three proposals build on the employer-based system. As stated by Senator Baucus,

We must ensure the continued viability of the employer-based system—the principal source of health coverage for most Americans—to allow workers to keep the insurance that they currently have and value. Eliminating employer-based coverage, as some have proposed, would upend health care for more than half of the American people—159 million in all. This plan envisions a role for employers to contribute to employees’ access to health care.

63. CALL TO ACTION, supra note 22.
64. Id. at 9.
65. See Obama Plan, supra note 22.
67. The plans by Baucus and Obama both use the term “National Health Insurance Exchange” while the Building Blocks framework uses the term “Connector.” See, e.g., Call to Action, supra note 22, at iv (“Health Insurance Exchange”); Obama Plan, supra note 22, at 3 (“National Health Insurance Exchange”). Schoen et al., supra note 66, at 1 (“a national insurance connector”).
68. See, e.g., CALL TO ACTION, supra note 22, at 13.
69. Id.
The Baucus Plan envisions that the majority of employers would continue to provide health insurance benefits and that people who have coverage through their employer or otherwise could keep that coverage. This is good news for the significant number of workers with chronic illness who have employer-based coverage. Maintaining the employer-based system—at least in the absence of an acceptable alternative—is also in alignment with public opinion, as between 63% and 81% of respondents in one survey thought a move away from employer-based insurance and into the individual market would make things worse for them. Building upon the existing system preserves the advantages of employer-based health care, including increased risk pooling, lower premiums and administrative costs, greater expertise and negotiating power, ERISA and HIPAA protections discussed above, and ease of payment through payroll deduction. The Baucus Plan also contains an employer mandate, commonly referred to as a “pay or play” provision: except for small businesses, employers who do not provide health insurance benefits would be required to contribute to a fund that would help cover those who remain uninsured.

Of course, as discussed above, a proposal that addresses the employment-based system in isolation fails to address the fact that employer-sponsored coverage is increasingly unstable for many workers and that without access to group coverage or a public program, many people, including people with chronic illness, are unlikely to secure individual coverage at any price. Under the Baucus Plan, people without access to employment-based coverage, including employees of small businesses that are unable to offer coverage, could obtain coverage through the Health Insurance Exchange (the Exchange), a nationwide insurance pool. The Exchange would include a structured selection of private insurance plans as well as a public plan option. Once the Exchange was able to provide adequate and affordable coverage options for all, an individual mandate would be

70. See supra note 8 and accompanying text and text accompanying 14 and 15.
71. See supra note 8 and accompanying text and text accompanying 14 and 15.
72. See supra note 8 and accompanying text and text accompanying 14 and 15.
73. The Baucus Plan and the Obama Plan suggest that the contribution be based on a percentage of payroll earnings taking into account the size and annual revenues of each firm. CALL TO ACTION, supra note 22, at 16; Obama Plan, supra note 22, at 5-6. The Building Blocks proposal suggests a payroll tax of 7% of earnings, up to $1.25 per hour. Schoen et al., supra note 66, at 649.
74. The public plan option, similar to Medicare, would be subject to the same requirements in terms of rating practices and benefits packages.
instituted, possibly enforced through the tax system.\(^75\)

At present, in an unregulated individual market, people with chronic illness are offered coverage at prohibitively high rates, or denied coverage altogether. Under the Baucus Plan, insurers participating in the Exchange would have to meet certain federal standards with respect to rating practices established by a new Independent Health Coverage Council.\(^76\) These standards are designed to provide individuals with protections often lacking in the individual market and to ensure broad risk-pooling within groups. Several of these relate directly to the experience of the chronically ill: for example, insurers participating in the Exchange could not exclude or consider pre-existing conditions. Insurers also would be required to meet certain standards with respect to coverage, as established by the Council. Differences in price would be based on differences in benefits, rather than the actual or perceived health status of anticipated enrollees, and insurers would be required to offer the coverage at the same price inside and outside the Exchange.

The Independent Health Coverage Council would also implement strategies to minimize adverse selection by individuals with high health care costs as well as “cherry picking” of individuals with low health care costs within the Exchange,\(^77\) such as requiring employers to enroll all employees for coverage through the Exchange, not just those with the highest health care costs.\(^78\) Similarly, the Building Blocks proposal suggests community or modified community rating and a guaranteed issue requirement in order for an Exchange to operate in a given state.\(^79\) In addition, the Obama Plan includes a proposal to reimburse employer-based health insurance plans for a portion of any catastrophic expenditures, as long as such reimbursement is used to reduce employee premiums, a feature which could benefit employers of chronically ill workers.\(^80\)

Affordability is a key issue, as people with chronic illness use more

\(^75\) President Obama’s plan currently includes a mandate only for children. See Obama Plan, supra note 22, at 5.

\(^76\) Under the Baucus Plan, insurers participating in the Exchange also would be subject to state consumer protection laws, such as requirements regarding “grievance procedures, external review, oversight of agent practices and training, market conduct.” Call to Action, supra note 22, at 18.

\(^77\) Adverse selection is a process by which people who have higher health care costs seek health insurance at a disproportionate rate to people who have (or think they have) relatively lower health care costs. See Peter Siegelman, Adverse Selection in Insurance Markets: An Exaggerated Threat, 113 Yale L.J. 1223 (2004). “Cherry picking” refers to the practice of offering coverage only to people who have or are perceived to have lower health care costs.

\(^78\) Call to Action, supra note 22, at 17.

\(^79\) Schoen et al., supra note 66, at 650.

\(^80\) Obama Plan, supra note 22, at 2, 5.
necessary health care services and bear more out-of-pocket costs even when insured. “Affordability” would be defined by the Independent Health Coverage Council, and refundable tax credits would be available to individuals and families with incomes at or below four times the federal poverty level—which would mean at or below $88,200 for a family of four— for the purchase of coverage through the Exchange. Small businesses would be offered a structured tax credit for the purchase of employee coverage through the Exchange. The Council would also be empowered to protect enrollees against high health care expenses, including out-of-pocket costs.

The tax-treatment of employer-based benefits also impacts affordability. Currently, employees are not taxed on the value of the job-based health insurance benefits. Some, including Senator Baucus, have suggested capping the income tax exclusion for workers or eliminating the exclusion entirely in favor of a tax credit or tax deduction for coverage from any source. Capping the exclusion could create new inequities for people with chronic illness, as well as others whose benefits exceed the cap for reasons other than comprehensiveness of their coverage. Attempts to offer and select coverage with a value under the cap might also result in a further decline in the offer, selection, and use of comprehensive coverage, which could be detrimental to those with high health care costs. As one author has noted, “it could be challenging to determine alternative tax benefits to replace the exclusion without adversely affecting


82. See CALL TO ACTION, supra note 22, at 19.

83. The employer’s contribution is excluded from an employee’s income for tax purposes, and the employee’s contribution can be excluded as well if made through a cafeteria benefit plan under Section 125 of the Internal Revenue Code. 26 U.S.C. § 106(a) (2000). For an overview of this issue, see BOB LYKE, CONG. RESEARCH SERV., THE TAX EXCLUSION FOR EMPLOYER-PROVIDED HEALTH INSURANCE: POLICY ISSUES REGARDING THE REPEAL DEBATE 1 (2008), available at http://www.allhealth.org/BriefingMaterials/RLS34767-1359.pdf.


85. See FRONSTIN, supra note 84 (noting that the value of health coverage might be above the tax cap due to variation of cost by employer size, employee health status, average age, and geographic region).

86. Id.
people with high costs.”

Consideration of the chronically ill also reminds us to look at the costs borne by public programs such as Medicare and Medicaid, and the Baucus Plan includes suggestions to strengthen public programs. For example, under the Baucus Plan and the Building Blocks framework, people aged fifty-five to sixty-four would be permitted to buy into Medicare until their coverage needs could be met through the Exchange, and the two-year waiting period for people with disabilities would also be phased out. Medicaid would be expanded to cover everyone living below the federal poverty level, and SCHIP would cover all children at or below 250% of poverty.

Apart from issues of financing and insurance, there is also a focus on improving the health care delivery system, including the prevention and treatment of chronic disease. This is proposed as part of an overall effort to improve care and lower costs: “National spending on health care can be lowered, and quality improved, by realigning the health care system toward prevention and primary care, rewarding providers that deliver quality, evidence-based care, and investing in critical research and health information technology that can lead to higher-value health care.” Under the Baucus Plan, the Independent Health Coverage Council would set standards for chronic care management and quality reporting, and insurers in the Exchange would collect and report on the performance of providers in their networks in order to allow comparison by consumers, the Council, and other regulatory entities. The Obama Plan provides that it will improve coordination and care for people with chronic conditions through disease management, team care, and medical home models. There is also a focus on preventative services, which would be covered by all options available through the Exchange. Medicare, Medicaid and SCHIP recipients would be eligible for these services at little or no out-of-pocket cost, as would people without insurance until they are able to secure coverage through the Exchange. While there is debate as to whether such measures would achieve cost-savings, there is evidence that they could improve care and outcomes for

87. See Lyke, supra note 83, at 12.
88. The Obama Plan, like the Building Blocks Plan, also emphasizes prevention and chronic disease management. See Obama Plan, supra note 22.
89. See Call To Action, supra note 22, at 65-66. The Baucus Plan also looks to lower costs and curb excess spending by: reducing health care fraud, waste and abuse; increasing transparency regarding costs of care, quality of care, and relationships between providers and drug and device manufacturers; reform of medical malpractice laws; eliminating overpayments of private insurance plans in Medicare; reorientation of long term care, including home and community based care; and fair distribution of tax incentives to provide care.
90. See Obama Plan, supra note 22, at 2-3.
91. See, e.g., Goetzel, supra note 36 just short-term costs-savings.; Louise B. Russell, Preventing Chronic Disease: An Important Investment, But Don’t Count on Cost Savings. HEALTH
people with chronic illness.  

CONCLUSION

Health care reform is critical. Heath care spending accounts for nearly one-sixth of the national economy, and the Congressional Budget Office recently projected that without changes that number will rise to nearly one-fifth, or almost $4.3 trillion a year, by 2017. Peter Orszag, now director of the Office of Management and Budget, argued in 2008 that rising health care costs represent the "single most important fact influencing the Federal government’s long-term fiscal balance."

As the nation struggles with rising health care costs, the rising incidence and prevalence of working-age people with chronic illness is cause for concern, in part because we know too little about it. In order to design an adequate response to the problem of chronic illness, we need to know who is bearing what cost. The cost does not fall on the sick alone—it is borne by families, employers, landlords, lenders, creditors, and our entire society. It is not an individual problem, and it seems we are paying for it anyway, often inefficiently and with poor results.

Chronically ill workers also illustrate some basic truths about the employer-based system, and remind us of some key points to consider for reform. Employer-based coverage is still an important source of coverage, and will remain so unless and until we have a suitable alternative. Damaging this system without a suitable alternative would disrupt coverage for the majority of the insured, including as many as 65 million people with chronic illness. At the same time, looking only at employer-based plans—simply one part of a complex, haphazard and inadequate series of coverage arrangements—prevents us from moving forward with informed discussions about more equitable ways to improve cost, access and quality of health care for every one, including people with chronic illness.

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92. See Katie Coleman et al., Evidence on the Chronic Care Model in the New Millennium, Health Aff., Jan.-Feb. 2009, at 75.
95. Call to Action, supra note 22, at 1 (citing Peter R. Orszag, Cong. Budget Office, Growth in Health Care Costs (2008)).
96. Hoffman et al., supra note 1, at 1474 ("Despite concerns about the costs of managing chronic conditions, there are few sources of data that allow us to weigh the overall economic and social impact of chronic conditions.")
The experiences and challenges of chronic illness in the workplace provide an opportunity to examine the larger framework of health care reform, not just the employer’s role in isolation. There is a national interest, one that employers share, in striking a better balance between caring for the chronically ill and controlling costs. Although many important elements are yet to be defined, comprehensive reform efforts such as that proposed by Senator Max Baucus attempt to strike that balance and to learn from the lessons of chronic illness in the workplace and the health care system.