



**Consumers for
AFFORDABLE
Health Care**

*Advocating the right to quality, affordable
health care for every man, woman, and child.*

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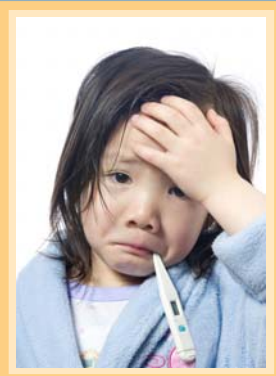


False Security

**Health Insurance That Doesn't Pay
When You Need It Most**

Mitchell Stein, MBA

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Acknowledgements and Thanks

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About the Authors

Mitchell Stein, MBA

Currently working as an independent consultant, Mitchell previously worked here in Maine as the Director of Program Coordination for Health Dialog and before that in New York for Mercer Human Resource Consulting, Inc. as their Global Intranet Director and as the Marketing Manager for US Health Care Practice. He is a Health Care Industry professional who focuses on strategy, marketing and product development. He has extensive background working with various aspects of the health care environment including insurance benefits designs. Mitchell holds a MBA from the University of Chicago. Mitchell lives in Cumberland Foreside with his wife, Martha.

Joseph Ditré, Esq.

Joe has 26 years of experience in researching and analyzing private and public health insurance policies and programs. Since its founding in 1988, Joe has directed and managed the general operations of Consumers for Affordable Health Care and has provided policy and legal analysis. He has been appointed to numerous commissions and task forces by both Democratic and Republican Governors. He is co-author of *At Risk: Small Business Health Insurance in Maine* (1999) along with Christopher St. John and Lisa Pohlman of the Maine Center for Economic Policy and has co-authored the following three reports with Hilary Schneider: *Off the Charts: Unsustainable Hospital Cost Growth in Maine* (2004), *When, Where and How Much: Improving Maine's Certificate of Need Program* (2004), and *Briefing Book to the Guiding Principles for Health Reform* (2005). He graduated from the University of Pennsylvania Law School in 1983. Joe lives in Manchester with his wife, Dyan, and two daughters, Maggie and Rosie.




About Consumers for Affordable Health Care

Our Mission

Consumers for Affordable Health Care assists individuals and organizations working together to advance the following goals: Achieve a system of universal health care providing the full range of care for all Maine citizens, including preventive and primary care, acute and long-term care; Achieve a system of health care and coverage financed from a broad variety of sources, both public and private, based on the income of businesses and individuals, which provides care based not on ability to pay but only on the need for health services; Moderate the rising costs of health care for all Maine citizens, while preserving quality; Ensure the availability of coverage, which protects the individual's right to freely choose her or his provider and method of care; Ensure a strong consumer voice in decision making at all levels and in all forums to provide for a consumer-oriented health system in Maine.

How We Accomplish Our Mission

Since 1988, Consumers for Affordable Health Care (CAHC) has been a leader in efforts to expand access to health coverage, to lower costs, and to protect and represent the interests of health care consumers. CAHC engages in a sophisticated and powerful mix of activities to advance strategic health reform. Our staff members advocate, educate, communicate, litigate, and organize for social change. CAHC operates a unique statewide toll-free HelpLine that takes over 2,000 calls per year. It assists people in need of affordable health coverage to complete MaineCare and other application forms and helps them navigate our health system. CAHC's Outreach and Education Program travels to all 16 counties throughout the year and provides trainings and workshops on MaineCare and other coverage options and involves interested people in our reform efforts. Consumers for Affordable Health Care's Coalition has 34 member organizations and small businesses representing the interests of over 200,000 Mainers. Our coalition members help us to extend our values, voice and vision into diverse communities throughout Maine.



Consumers for Affordable Health Care

Coalition Members

| | | |
|---|---|----------------------|
| Avalon Group | National Alliance for the Mentally Ill | Fred Pease |
| Chase Home Furnishings, Inc. | National Association of Social Workers—ME Chapter | Gary & Ann Keilty |
| Direct Care Alliance, Inc. | National MS Society—Maine Chapter | Georgine Butman |
| Disability Rights Center | New England Hemophilia Association | Janet S. Houghton |
| Eastern Area Agency on Aging | New England Regional Council of Carpenters | John L. Beauchamp |
| Family Planning Association of Maine | Penquis | John Henderson |
| Hummingbird Home Care, Inc. | Planned Parenthood of Northern New England | John S. O'Brien |
| Kennebec Valley Organization | Roman Catholic Diocese of Portland | Lars Rydell |
| Law Office of Alice E. Knapp | The Pond Pool of Wellness | Lisa Littlejohn |
| M.A.I.N., Ability Maine | WCAP | Mark Battista |
| Mabel Wadsworth Women's Health Center | Western Maine Community Action, Inc. | Martha J. Morrison |
| Maine AFL/CIO | Anne C. Patenaude | Mary Ann Larson |
| Maine Association of Substance Abuse Programs | Becky Martins | Mitchell Stein |
| Maine Center for Economic Policy | Brian Atchinson | Patrick Patterson |
| Maine Council of Churches | Clifford Ginn | Poppy Thacher Arford |
| Maine Council of Senior Citizens | David & Barbara Weiss | Rosemary Fecteau |
| Maine Equal Justice Partners, Inc. | David M. Johnson, D.O. | Roy Gedat |
| Maine PASA | David P. Frasz, MD | Ruth Dean |
| Maine Parent Federation | Deb Klane | Sally Sutton |
| Maine People's Alliance | Douglas J. Rooks | Scott Ruffner |
| Maine Primary Care Association | Dr. Susan Cook, PA | Susan Fesenmaier |
| Maine Women's Lobby | Elizabeth Hart, MD | |
| MSEA—SEIU Local 1989 | | |



Continuing the Path to Reform

One year ago, Consumers for Affordable Health Care published a report entitled ***A Call to Action on Health Care Reform in 2009: The Transparency Imperative***.¹ It began “Costs are up. Jobs and wages are down.” Sadly, that is still the case. As a result, Maine’s working families and small business owners are still struggling to balance their checkbooks, keep food on the table, pay back loans and their mortgages, and pay for needed medical care and prescription drugs. ***Costly Coverage: Premiums Outpace Paychecks in Maine***, a report published in August 2009 by Families USA documents that from 2000 through 2009, family health insurance premiums for Maine’s workers rose 4.6 times more quickly than median earnings. On average, health care premiums for families rose by more than 101%, while median earnings rose by only a little more than 22%.²

These facts, repeated in virtually every state throughout the U.S., compelled President Barack Obama to urge the Congress and our nation to act. Today we stand on the brink of the President signing the most sweeping health care legislation since the enactment of Medicare and Medicaid more than four decades ago. It is designed to drastically reduce the number of uninsured as well as improve the quality of health care and health insurance available. Maine provided a lot of

lessons to its people and other states’ Congressional delegations about health reform. Maine is a model for national health reform. Almost all of Maine’s major consumer protections were included by the bi-partisan “Group of Six” in their national health reform bill and are included in the bills that recently passed in the House and Senate. The Group was made up of three Republican and three Democratic Senators on the Senate Finance Committee including Sen. Olympia Snowe. For example, Maine was the first state in the nation to prohibit long waiting or exclusionary periods for pre-existing conditions (1990). Maine prohibits insurance companies from charging higher rates to women or people with medical conditions (1993). Maine limits how much more an insurance company can charge an older person compared to a younger person for the same policy (1993). Maine requires insurance companies to offer and renew coverage for anyone who wants coverage and will pay the premiums (1994). The state enacted the nation’s first transparency law that requires insurance companies to report revenues and expenses in an apples-to-apples format for all lines of insurance (2003). Maine requires insurance companies to provide the certificate of coverage to people before the consumers buy the coverage (2009). The state enacted the nation’s first statewide subsidized health coverage program called Dirigo Health (2003). Maine expanded MaineCare, Maine’s Medicaid program, to cover more children and

their parents (2000). All of these and other efforts have helped reduce the number of uninsured in Maine and keep insured Mainers from losing coverage. According to United Health Foundation's 2009 report, Maine ranks in the top six states in the country for insuring the most people and ninth best in health determinants and outcomes.³

This year, Maine could take another positive step in its efforts to protect consumers and patients. This report describes factors that are driving Maine consumers and patients into bankruptcy or extreme medical debt — lifetime and annual caps on health benefits. In the following pages we'll define those limits, explain who is hurt by them, and discuss the great benefit and limited impact of eliminating them.



What are Annual and Lifetime Limits?

An annual limit is the maximum amount that health insurance plans will cover in claims for their members during a one-year period. A lifetime cap is the total amount an insurer will pay for the policyholder's life or as long as they hold that plan with that specific insurer. These caps are different from limits on benefits for specific services, such as a plan allowing only 20 physical therapy visits per year. Annual or lifetime benefit limits are aggregate (accumulated) spending limits placed on total insurance benefits; once they are met, the policy no longer provides coverage for any services - the costs are on you.

Lifetime caps were first established by the insurance industry in the early 1970s with a standard amount being \$1 million. Forty years later, it's not uncommon to still see the same dollar limit even though a \$1 million lifetime cap in 1970 when adjusted for medical inflation⁴ would be more than \$10 million. Lifetime caps have not changed as the cost of health care coverage and services have skyrocketed leaving policyholders vulnerable to crushing medical debt.

Most people are unfamiliar with these limits and thus unaware that their health insurance could expire when their health care costs have totaled a certain amount. Individuals and

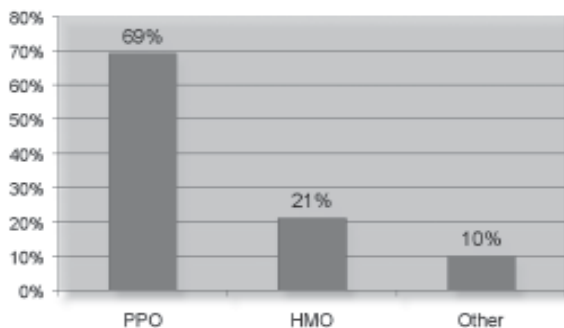
families then must: pay for their health expenses out of pocket, spend down their assets to qualify for Medicaid - if eligible, or try to seek free care from hospitals or other providers. This threatens both the physical and economic health of the individual and their family.

More than half of people covered by employer-sponsored health plans are subject to some type of limit. The US Census Department reported in 2008 that 58.5% of the population is covered by employer-sponsored coverage as opposed to 8.9% who directly purchase coverage on their own. The rest of the country's population is either uninsured or covered by government plans such as Medicare, Medicaid or Veterans/Military benefits.⁵

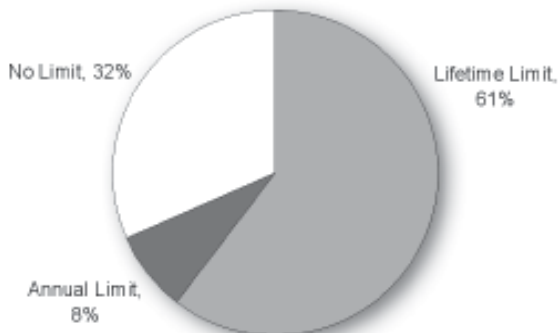
Specifically, from Mercer's 2009 National Survey of Employer-Sponsored Health Plans, we see that among PPO (Preferred Provider Organization) plan sponsors — **61% impose a lifetime limit and 8% have an annual limit.** The median limit amounts are **\$2.5 million for lifetime and \$1 million for annual limits.** In 2009, PPOs represented 69% of the health plans offered. Twenty-five percent of HMO (Health Maintenance Organization) plans impose of a lifetime limit, and 14% impose an annual limit. HMOs represent 21% of the plans offered nationally.⁶

A March 2009 report by PricewaterhouseCoopers, which focused on lifetime limits, reported similar numbers estimating about 55 percent of individuals with employer provided health insurance are subject to lifetime limits which amounts to about 91 million people on such plans in 2009.⁷

Employer-Sponsored Health Plan Enrollment (Nationally)



Among PPO Plans (Nationally)



◆ *Totals more than 100% due to rounding

What is the Risk or Potential Harm to Insured Consumers and Patients?

We can see from the above statistics that there are many people with health insurance who are subject to annual or lifetime limits. But what is the risk or potential harm? Why do these caps need to be eliminated?

In February 2009, Senators Byron Dorgan (D-ND) and Olympia Snowe (R-ME), introduced legislation to raise lifetime caps to a **minimum of 10 million dollars**. In their press release they stated:

“Having an inadequate lifetime cap defeats the purpose of health insurance and forces those with disabilities and chronic illnesses into an impossible situation,” said Dorgan. “Low caps also end up costing the taxpayer because once people with illnesses hit their cap, they often turn to government programs for their care. This legislation will raise lifetime insurance caps and allow those with illnesses to focus on recovering - not worrying about how they are going to pay for their treatment.”

“Low lifetime caps can mean financial disaster for people with chronic illnesses,” **Senator Snowe** said. “Overly restrictive lifetime caps on benefits can cause everyday Americans to go bankrupt and ultimately shift their health care costs to public programs, such as Medicaid. This legislation will provide the immediate financial and psychological relief to families who struggle to access health care in the midst of an expensive and life-threatening medical crisis.” (Emphasis added)⁸

To protect the health of every individual means we must protect both their physical and financial health. According to the study “Medical Bankruptcy in the United States, 2007”, 62% of all bankruptcies that year were related to unaffordable medical bills. The same study stated that *69% of those people claiming bankruptcy had health coverage at the time of their bankruptcy filing.*⁹

The presence of annual and lifetime limits contributes to this situation. While clearly not the only factor, in some cases these limits are responsible for causing catastrophic damage to

an individual's physical and financial well being, even though the individual had health insurance and thought they were protected.

Further we learn from Robert W. Seifert and Mark Rukavina in their *Health Affairs* Perspective that "bankruptcy is the tip of a medical-debt iceberg."

"Medical bankruptcy, whatever its actual frequency, is an extreme example of a much broader phenomenon. Medical debt is surprisingly common, affecting about twenty-nine million nonelderly adult Americans, with and without health insurance. The presence of medical debt, even for the insured, appears to create health care access barriers akin to those faced by the uninsured. Policymakers, researchers, and medical providers should consider medical debt a risk factor for reduced health access and poorer health status. Simply reducing the number of uninsured Americans would be a hollow policy victory if the problems arising from medical debt persist."¹⁰

Everyone who is covered by a plan with either annual or lifetime limits is at risk of catastrophic impact on their lives if they reach the limit. The individuals who reach their limit will suffer great harm. Worse, this happens to the most vulnerable among us, those suffering an acute illness like cancer, a disability, or a chronic illness like hemophilia.



How Can an Individual Accrue Several Million Dollars in Medical Expenses?

Suffering from cancer is one way that one's health care expenses can reach astronomical heights.



An example reported in the Los Angeles Times was Michael Treinen from Indiana:

Michael, a teenager, was diagnosed with an aggressive form of leukemia. His treatment required 10 doses of a chemotherapy drug that cost \$10,000 per dose and a 56-day stay in an intensive care unit that cost \$400,000 dollars. Michael reached his family's lifetime maximum in less than a year. The hospital informed the family they needed either \$600,000 in certified insurance or a \$500,000 deposit to move forward with Michael's bone marrow transplant. Despite eventually receiving financial support from the community, Michael died before he could receive the transplant. Today, his family continues to pay for the cost of Michael's treatment.¹¹ (Emphasis added)

People suffering from hemophilia also often quickly accrue high medical bills. The National Hemophilia Foundation reports that costs for clotting factor medications are typically

\$250,000 a year per person or more.

However, bleeding from a trauma, surgery, the development of an inhibitor (immune response to treatment), or a variety of other complications can elevate costs in a given year to \$1 million or more.¹²

As stated in a letter by the Raise the Cap Coalition, "Individuals with chronic diseases and disorders must not be impeded in accessing necessary health care nor should they be impoverished with unreasonable lifetime limits on benefits."¹³



Theresa D'Andrea knows first hand how devastating reaching a lifetime limit can be:

Theresa and her husband live in **Maine** and worked hard their whole lives—paid their taxes, and he even served in the Army during the Vietnam War. But now they are in financial ruin. They're in danger of losing their house, their credit cards are maxed out, and they still have growing debt—all because he got sick. Their horrors started in September 2008 when he was diagnosed with "menastic melanoma" (stage four skin cancer that has spread to other body parts). They were told their only hope was an experimental drug that cost nearly \$9,000 per dose. He had to take four of those a day for four weeks. After the four week hospital stay they were left with a bill for \$1.6

million. Their insurance had a lifetime cap of \$250,000—so they “capped out” in mere days. Once hospitals, drug companies and other medical care providers realized they were “out of insurance” they worked with the couple to reduce their bills. They now owe about \$45,000. But, ongoing care continues to add about \$4500 more a month on that tally. Because he is so sick, he did qualify for social security disability, which qualifies him for Medicare. Unfortunately, there’s a two year waiting period for that health coverage—and the couple must face the reality that he likely will not be alive to see the day when that insurance will kick in.



What is the Impact on Insured Consumers and Patients?

As discussed above, many individuals are at risk, but how many are impacted each year? According to the PricewaterhouseCoopers study, nationally between 20,000 to 25,000 people reached their lifetime limits in 2009.¹⁴ Maine had less than one-half of one percent (0.43%) of the total US population as of July 2008.¹⁵ If the 25,000 people who reach their benefit limit were evenly distributed, it would mean about 108 people in Maine exceeded their benefit limit last year. The estimate likely would be higher if individual policyholders were included in the above estimate, which is based on employer-sponsored coverage.



That’s more than 100 people that can be saved from financial ruin, or worse. But what will the impact of eliminating these limits be?

We’ve seen that while many people are at risk, relatively few people actually exceed their insurance limits. So, the cost of significantly increasing or effectively eliminating those caps would be minimal—but the amount of difference it makes for those affected families is immeasurable. PricewaterhouseCoopers estimates, based on the current distribution of plans and their lifetime limits, that the overall

cost increase for all insurers with lifetime limits would be 0.4 percent to 0.6 percent for significant limit increases.¹⁶

The Kaiser Family Foundation reports that it costs \$4,824 for an individual and \$13,375 for family health coverage per year under an employer-sponsored insurance plan.¹⁷ If insurance industry estimates are correct, and insurers decide to pass this increase onto its policy holders, the impact of eliminating lifetime caps could add about \$2 a month for an individual policy holder and \$5.50 a month to family plan premiums. A small price to pay to eliminate such a catastrophic risk for our hard working families!



Proposals to Eliminate or Raise Lifetime and Annual Caps

In May 2009, Senator Rockefeller (D-WV) went further than the Dorgan-Snowe bill discussed previously. He introduced the “Annual and Lifetime Health Care Limit Elimination Act of 2009,” which would eliminate lifetime and annual caps altogether for the country.

This concept has been included in the national health reform legislation passed by both the House and Senate in Washington, D.C. In the case of the Senate, it was the result of last minute negotiations and a correction in the “Manager’s Amendment.” However, while it seems these cap elimination provisions will be included in final legislation, at the time of this report’s publication (January 2010) the final bill has not been drafted. Further, it’s possible that those changes may not take place **for years**.

We must eliminate the risk of annual and lifetime caps on Maine residents immediately, not at some indeterminate future date.

Policymakers in Maine will have the opportunity to address the subject of this report - lifetime and annual limits on insurance benefits - when the Maine Legislature considers proposed legislation regarding those limits in 2010.

Maine has been a leader in advancing important consumer protections, many of which are included in the national health reform proposals advanced by Democrats and Republicans in Congress. We need to work together in a bipartisan manner to address outdated, ineffective, and harmful policies that can inflict tremendous financial burden and sometimes financial ruin on Maine's individuals and families. This report shows that for very minimal costs, Maine can protect its insured residents from catastrophic health care costs when illness strikes. You and your family deserve to have such protections.





Making it Happen: A Call to Action!

We invite you to join **Maine Voices for Coverage**, a statewide campaign to bring the views and ideas of “every day people” to policymakers to ensure that all Mainers have access to quality, affordable health care that is there when they need it.

Consumers need to play a critical role in shaping health care reform initiatives. It is vital that consumers have a seat at the table alongside insurers, drug companies, hospitals, doctors and other providers, and businesses that currently affect health policy as necessary reforms such as those on transparency and cost-containment move forward. The well-funded and well-organized voices of insurers, hospitals and big business must be balanced by the active participation of consumer advocates, who represent the needs of those using the health insurance system as well as those who are currently shut out of it. Having the participation of health providers, who want to provide high quality, affordable care to their patients is key to our success too.

Maine Voices for Coverage is formed around the principles that health care and coverage must be:

- Guaranteed to all.
- Affordable and available for everyone.
- Comprehensive and high-quality to meet people’s needs.
- Simple to use for the consumer and provider.
- Flexible, providing the patient with choice of provider.
- Paid for with shared responsibility from individuals and businesses.
- Transparent and accountable to Maine people.

The following organizations are leading **Maine Voices for Coverage**: Consumers for Affordable Health Care, Maine Equal Justice Partners, Maine People’s Resource Center, Maine Center for Economic Policy, American Cancer Society of Maine, Maine Council of Churches, Maine Parent Federation and the Maine AFL-CIO.

Transforming our health system will only happen when consumers are engaged and have an organized and coordinated voice. Speaking with a unified and amplified voice will enable consumers to harness their collective power, build momentum and keep health reform high on the political agenda.

Efforts to expand health care access require compromise and consensus among key stakeholders, including providers, government, business and consumers. We need to work *together* to find solutions that benefit *all* Maine people. Efforts without a consumer voice, insight, and actual experience will only continue to develop and promote a system that is business-centered rather than patient-centered. To achieve meaningful reform that will truly benefit Maine people, solutions must be created with the input of those who navigate the health care system.

At the end of the day, we are all consumers and we all ultimately foot the bill for our health care system. We sit at the table to represent different interests; however, whatever is in the best interest of the consumer is in the best interest of us.



(Endnotes)

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