Summary

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Long-Term Services and Supports as Part of Health Care Reform: Relief for the Invisible Uninsured?

A One-Year Review of the 2008 Conference Roundtable Prepared by Lee Goldberg*

The recent presidential election demonstrated a broad interest in health care reform focused on access to affordable quality care and cost containment for both public and private-sector payers. So far, the policy debate has centered on the delivery of acute care services, rather than long-term services and supports (LTSS). But there is a strong case that health care reform will not succeed unless LTSS are also addressed.

- LTSS is an area of growing demand. Today, there are approximately 13 million people who need LTSS. By 2050, the number of individuals using paid LTSS in any setting (e.g., at home, residential care such as assisted living or skilled nursing facilities) will reach 27 million people. The greatest growth will be in the population of people age 85 and older a segment of the population with significantly higher utilization and acuity rates (The SCAN Foundation, 2008).
- LTSS is a major cost driver. According to the Center for Medicare and Medicaid Services (CMS), LTSS paid by Medicaid totaled \$231 billion in 2006 and is projected to grow faster than the economy as a whole. Medicaid has become the largest or second largest item in states' budgets, often crowding out other spending priorities. Although the program is a cost-effective way to provide health and long-term care services to individuals who either cannot afford or do not qualify for private-sector coverage, the increasing burden of LTSS is not sustainable for the 49 states that have to balance their budgets. Medicaid is a smaller portion of the federal budget, but the aging of the population will continue to increase federal program costs during a time of large federal deficits.
- Outside of Medicaid, few people have coverage for LTSS, despite the fact that the lifetime probability of not being able to perform at least two activities of daily living or of being cognitively impaired is 68 percent for people age 65 and older (Gibson, 2003). Less than 15 percent of individuals have private long-term care insurance, even though a majority of individuals will have at least \$25,000 in total LTSS costs (American Association of Homes and Services for the Aging, 2006).

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Yet there is not the same sense of urgency around access to affordable LTSS that exists over the lack of primary and acute care coverage for 47 million working-age Americans and their families (Glied and Mahato, 2007). Certainly, there is no recognition that far more people are uninsured for LTSS than for acute care.² In the current policy debate, they are the invisible uninsured.

What will it take to include LTSS as part of a health care reform effort that is focused primarily on coverage expansion and cost containment? When President Bill Clinton's health care reform proposal failed, so did a proposal for a major expansion of home care for people with chronic care needs. Fifteen years later, the dysfunction of the health care system has grown more apparent. There is renewed interest in comprehensive reform, and there is concern about whether health care reform that provides universal coverage for acute and primary care will fully succeed without improvements in long-term services and supports.

At its 2008 annual policy conference, *Getting to Universal Health Insurance Coverage*, the National Academy of Social Insurance (NASI) brought together several LTSS policy experts to offer insight on how long-term care policy might again attract national attention. **Lee Goldberg** moderated the panel and wrote this report. The other members of the roundtable panel were **Chris Jennings**, President of Jennings Policy Strategies, Inc.; **Robyn Stone**, Executive Director of the Institute for the Future of Aging Services; **Stephen McConnell**, then Vice President for Public Policy and Advocacy at the Alzheimer's Association; and **Ron Pollack**, Executive Director of Families USA.

This brief reviews past efforts to reform LTSS, considers the current political environment for LTSS reform and proposes several general recommendations. The experts on last year's panel believed that health care reform would provide an opportunity to achieve incremental but significant reforms to the current system of LTSS. Subsequent research leads to the following recommendations for LTSS reforms that fit naturally within the framework of health care reform:

- 1. Improve care coordination for people with multiple co-morbidities. Legislation introduced in the 110th Congress adding a chronic care coordination benefit (S. 1340/H.R. 2244) is a good starting point.
- 2. Analyze demonstration projects that integrate care for the dually-eligible and look for opportunities for further integration of both care and financing through Special Needs Plans, the expansion of successful programs like Evercare and the PACE programs or other initiatives that demonstrate improved health outcomes.
- **3.** Create a homecare benefit under Medicare. This could be achieved with changes to the home-bound rule and the two-year waiting period for people with disabilities under the age of 65.
- **4. Increase access to Medicaid consumer-directed home care** by amending the recently created 1915(i) state plan option, expanding the number of services allowed and easing eligibility requirements to make them consistent with eligibility limits in Medicaid waivers.
- 5. Expand the federal matching payment for Medicaid home and community-based services (HCBS) to help states to reallocate resources toward LTSS, which consumers prefer.

Introduction: The Possibility of Reform

Health care was a major issue for voters in the 2008 presidential election — inextricably tied to their own concerns about financial security in a slumping economy. Although foreign affairs and world financial markets continue to top newspaper headlines, health care reform that expands coverage, increases access to preventive care and contains costs continues to have staying power among voters.³ These expectations have not diminished, perhaps because President-elect Barack Obama was the one major party candidate who pledged to make health care reform a priority during the first 100 days of his administration (Ambinder, 2008).

There are clear indications that current efforts to achieve health care reform may be more successful than prior attempts. Stakeholder groups not only mobilized voters for the general election, but for the first time they are prepared to continue that same level of activism into a new administration, understanding correctly that the question of achieving universal coverage will be answered not in November 2008, but sometime during 2009 (Yglesias, 2008; SEIU, 2008).

The most important difference may be the strong congressional support for health care reform this time around, particularly in the Senate. President Clinton's proposal stalled when key chairmen were ambivalent and focused on other issues. This year the situation is quite different. Even before the start of the 111th Congress, Senator Max Baucus (D-MT), the current chair of the Finance Committee, released a 72-page white paper outlining in detail his vision of comprehensive reform. At the same time, Senator Ted Kennedy (D-MA), the chair of the Health, Education, Labor and Pensions Committee, has started working with colleagues on and off the committee to address key issues and organize support for comprehensive reform.

Today's Dilemma

The growing momentum for health care reform has not gone unnoticed among those advocates who have for decades sought expanded public coverage of LTSS. The question facing LTSS advocates is whether LTSS can be part of health care reform, even if a significant part of LTSS involves non-medical supports and services. Would proposals to change the financing of LTSS create an additional constituency for a reform movement that has so far been focused on working-age people and their families? If the time is not ripe for a consideration of LTSS financing reform, then are there at least significant incremental changes to the delivery of services for those with chronic care needs that would put us on a path to systemic change? And would the politics of long-term care support such half-measures? For example, would stakeholders settle for anything less than comprehensive reform of LTSS financing? And is there adequate agreement among thought leaders and advocates on what those policy milestones should be? These questions, raised by participants at a seminar sponsored by NASI in January 2008, are even more relevant today.

Current Landscape

The shortcomings of the financing and delivery of long-term services and supports are well known and have been documented at length. NASI's Long-Term Care Study Panel (Burke, Feder, and Van de Water, 2005) highlighted the key issues:

- *Unmet Needs*. Many people receive inadequate care. Nationally, 20 percent of people living in non-institutional settings who need services get less help than they need. As a result, they are more likely to fall, soil themselves or be unable to bathe or eat.
- Burden on Caregivers. Unpaid caregivers play a critical role in the system but often pay an unsustainable economic, physical and emotional price. Workers in the formal LTSS system labor under difficult conditions and low wages, frequently without fringe benefits.

- Financial Jeopardy. The cost of LTSS can impose financial hardships for many families. Home care can easily cost \$25,000 a year and institutional care can cost twice that. Since few families can qualify or afford private insurance coverage, this kind of care is typically paid for out of pocket.
- Limitations in Medicaid. The federal-state Medicaid program finances care only for those who are or have become impoverished. Its benefits vary widely from state to state, and it requires some people who need help to move to institutions when they would prefer to live at home.
- *Quality Problems*. Serious quality problems persist in some nursing homes, partly as a result of inadequate staffing and poor government oversight. Quality in non-institutional settings is also a concern.
- *Demographic Challenges*. The current system of LTSS is unprepared to meet the demands that the large baby-boom generation will impose upon it. The upcoming demographic shift will also exacerbate existing staffing shortages.

New issues have arisen. A strong consumer preference for HCBS has coincided with public concern about the quality of care in nursing homes, triggered anew by the financial upheaval in the industry and the turnover in facility ownership. Corporate buyouts by private equity firms have raised questions about accountability and transparency in an industry that receives approximately two-thirds of its funding from federal and state taxpayers. A 2007 story by the *New York Times* revealed the byzantine corporate structures employed by private equity firms and large chains to thwart private litigants seeking compensation for poor care (Duhigg, 2007).

Past Attempts at LTSS Reform

There have been earlier efforts to reform the financing and delivery of long-term services and supports. In 1988, Representative Claude Pepper tried unsuccessfully to add a home care benefit to the Medicare Catastrophic Coverage Act, but he did persuade the congressional leadership to broaden the mandate of the Bipartisan Commission on Comprehensive Health care Reform to include LTSS (Wiener, Estes, Goldenson, and Goldberg, 2001). Although Pepper did not live long enough to serve on the commission, its 1990 recommendations came out squarely for an insurance-based system for LTSS that included both HCBS and institutional benefits. Though well-reasoned and well-supported, the commission's LTSS recommendations did not have sufficient political support outside the commission to succeed. As one observer noted, a congressional commission does not a national dialogue make, and the bipartisan findings were never converted into popularly supported legislative actions (Citizens For Long-Term Care, 2001).

There have been efforts to increase the political visibility of LTSS reform to build popular support for federal action. In 1987, the Villers Foundation and AARP established Long-Term Care '88 – a coalition of more than 100 health and social service groups focused on raising awareness of the issue among Presidential candidates during the 1988 campaign through a series of interviews (Wiener et. al., 2001). Rather than surveying candidates, LTC88 sought to engage the candidates personally. LTC88 showed them each videos of families from early primary states struggling to meet the LTSS needs of loved ones. After the video, a peer would interview the candidate. The process connected candidates with the issue in a way that was unprecedented – at least one candidate was moved to tears – but the results were disappointing. The winner of the election, George H.W. Bush, was the only candidate who did not participate in the process (Goldberg, 2008).

Past legislative proposals for LTSS reform have fallen into four categories (Wiener, Illston, and Hanley, 1994):

- 1. **HCBS Only**. In 1993, Clinton offered a home care only benefit as part of his comprehensive health reform plan.⁵ Similar to the home care benefit proposed by Pepper in 1987, the Clinton plan provided a capped matching grant program for states to cover home and community-based services for people with severe disabilities, regardless of age.⁶ Nursing home benefits were not included in the LTSS portion of the Clinton health plan.
- 2. **Front-End Coverage.** In 1990, Kennedy offered a proposal to cover home care and six months of nursing home care. With limited public funding, the proposal directed resources to people living in the community and to those with the greatest chance of returning to the community. This was politically attractive because of its across-the-board appeal to voters whose major concerns were staying in the community and affording institutional care should that be necessary. Limits on the nursing home benefit avoided the government having to accept an open-ended liability of significant proportions. The benefit was constructed as an expansion of Medicare at a time when concern over the program's solvency was not as great.
- 3. **Back-End Coverage.** In 1992, Senator George Mitchell (D-ME) introduced legislation to provide home care benefits and nursing home coverage after a two-year deductible period. This home care plan with catastrophic nursing home coverage was based on the assumption that private insurance would be more affordable and more widely purchased if it was asked to cover a limited duration, and was seen simply as a stop-gap for public coverage. This was a policy rationale similar to the development of privately offered Medicare supplemental coverage. Under this approach, government provides coverage that the private market is reluctant to take on. But this back-end policy is a high-risk strategy for taxpayers because it relies on the transformation of a private insurance product that few elderly can afford in its current configuration.
- 4. **Single-Payer**. In 1988, Representatives Pete Stark (D-CA) and Henry Waxman (D-CA) introduced separate bills that offered universal comprehensive coverage for both institutional and non-institutional care after a relatively small deductible. Relying solely on the federal government; this plan avoids both private insurance and Medicaid. As a single-payer proposal, it may be better positioned to control costs and access to services but it requires popular embrace of an ideological view that is not yet evident.

More recently, there is a fifth option: what could be thought of as the **Long, Skinny Benefit**. In 2005, Kennedy and Senator Mike DeWine (R-OH) introduced a proposal to create a public insurance program that provides a lifetime benefit for individuals who become functionally disabled. The bill creates a cash benefit that is intended to supplement other sources of LTSS financing (either private savings or Medicaid). The benefit would vary based on the degree of disability and could be used to help individuals stay in the community or to offset a portion of the cost of institutional care. The program would not be means-tested and would be funded through voluntary payroll deductions. Individuals would be eligible for a benefit if they have contributed to the program for five years and have two or more impairments in Activities of Daily Living (ADLs) and/or the equivalent cognitive impairment.

None of these proposals has gained broad political support among federal policymakers or the public. Hearings have been held on the need for greater access to LTSS and on the shortcomings of the current system of financing. Experts have testified about the need to consider a federal insurance program that would spread risk, but none of these proposals has come close to passage

or been featured prominently during federal elections. When asked, the public has strong opinions about the current system, but that hasn't translated into a sense of political urgency (Burke, Feder, and Van de Water, 2005).

Lessons Learned

What do past efforts at LTSS reform tell us about the likelihood that LTSS will be included in health care reform in 2009?

Congressional Champions

Although many members of Congress have worked on LTSS policy, the conventional wisdom is that there are no legislative champions for LTSS in today's health care reform debate. There are key lawmakers who are strong proponents of a better LTSS system. Baucus has a vision of health care reform that explicitly includes changes to Medicaid that would increase access to HCBS. Kennedy has actively pushed for a version of the Community Living Assistance Services and Supports (CLASS) Act to be included in the Democratic health care reform bill. But at least at this early stage, there does not appear to be the equivalent of a Claude Pepper for whom financing LTSS would be a top priority in any comprehensive overhaul of the health care system.

In the past, the absence of a single-issue champion has been a decisive factor during the legislative endgame. In 1994, the lack of a champion for LTSS meant there was no one to salvage the home care provisions from the ashes of the Health Security Act – something arguably possible, since the LTSS provisions of the bill actually received more votes in the Senate Finance Committee than the coverage expansion provisions for acute care (Wiener et. al., 2001).

Executive Branch Leadership

Just as telling has been the absence of executive branch leadership during the intervening fourteen years. Will this change in the near future? President-elect Obama has endorsed progressive Medicaid reforms such as the Community Choice Act and he is a cosponsor of the CLASS Act. But it is not clear whether he will be willing to devote major resources to the issue as part of health care reform. As Robyn Stone, Executive Director of the Institute for Aging Services, commented during the NASI panel, opportunities for progress in long-term services and supports have existed only when there has been strong leadership from both the executive and the legislative branches. Outside observers have described the lack of strong leadership or a bold vision on this issue as the missing ingredient that is needed for a national dialogue (Stevenson, 2008).

Public Support

Increased public coverage of home care or nursing home care is a potentially expensive endeavor that would have a significant impact on incomes and savings. Kennedy's plan for a social insurance program would involve the movement of hundreds of billions of dollars annually into a trust fund, with a concomitant impact on personal savings and discretionary spending. Congress is unlikely to approve such policies without an extensive national dialogue around the underlying problem and alternative solutions.

It is not solely the responsibility of our elected leaders to stimulate this discussion. We have not seen a diverse set of stakeholders focus on LTSS in the same way that we have seen them focus on expanded coverage for acute care. We have not seen coalitions of political opposites coalesce. We have not seen the sustained media coverage that is necessary to create a sense of urgency about either the unmet needs or the hardships that are created by a means-tested approach to LTSS. There are few if any interest groups or foundations for which reform of LTSS financing is

a top priority. For most, comprehensive reform of LTSS financing is a secondary priority compared to expansion of acute care coverage or the more immediate legislative threats and opportunities that arise as part of the annual federal budget process.

As one panelist suggested, our current inertia reflects the lack of crisis that is often necessary for significant structural change in our political economy. The cost of Medicaid LTSS is a problem for states, though they are largely able to control spending on HCBS through waivers. Even with the current recession, state policymakers do not yet find themselves in the same fiscal bind that their German or Japanese colleagues did in recent years (Campbell and Morgan, 2005). LTSS is on the agenda for most state policymakers but in the context of budget cuts, not program expansion. State lawmakers are looking for federal assistance simply to maintain the status quo, not redesign or expand services to address unmet needs.

Policy Development

Part of the problem may also be that the debate over universal coverage for acute care has evolved in a way that is not yet true for LTSS. Past efforts to achieve universal coverage for acute care failed when the debate was framed as a moral obligation to improve the lives of fellow citizens, noted Steve McConnell, (former) Vice President for Advocacy and Public Policy for the Alzheimer's Association. Today, there is broad political support for the notion of comprehensive health care reform in part because advocates are discussing coverage expansion as a way to end cost shifting and contain costs. More importantly, there is broad, even bipartisan support for a "Massachusetts-type" model that includes a mix of insurance market reforms, Medicaid expansion and mandates on both employers and individuals. Questions remain about the role of the federal government in developing a national version of this model, but the intense ideological debate over how to finance coverage expansion seems to have waned. Indeed, one outcome of the presidential contest seems to be a clear lack of enthusiasm by voters for proposals to replace the income tax exclusion for employment-based health insurance with a deduction.

In contrast, reform of our system of LTSS remains mired in many of the ideological arguments that have stalled policy efforts in the past. The lack of progress on this issue is not just a matter of ignorance on the part of the public, i.e. a misguided belief that Medicare covers LTSS, though there is some of that. The larger reason is that there remains a fundamental disagreement over the role of government versus the market in ensuring greater access to LTSS; even those who favor a predominantly publicly-funded LTSS system do not agree which programs to expand or the scope of personal responsibility. Though more people understand the dysfunction of the current system, there is not yet a broadly shared view of what a new system should look like, nor a shared sentiment that inaction is worse than the status quo.

How LTSS Can Be Part of Health Care Reform

Although we may lack the public resolve necessary to support an overhaul of the current system of financing LTSS, panelists at the 2008 NASI conference agreed that the movement towards health care reform provides a major opportunity for significant progress on LTSS if the issues are framed correctly and the focus is fairly narrow. After all, we are in the midst of a health care reform debate that includes a number of LTSS issues, even if they are not labeled as such. As Chris Jennings noted, discussions of cost containment are really discussions about how to address the health care needs of those with chronic health conditions. This is the medical side of LTSS, where 20 percent of Medicare beneficiaries have five or more chronic conditions and account for almost 70 percent of all Medicare spending (Anderson, 2005).

What are some of the policy areas upon which the new administration can focus? First, there are a number of changes to Medicare that could help people with multiple co-morbidities. Discussion

of a "medical home" is not dissimilar to what LTSS advocates have recommended for years in terms of more robust case management services for those eligible for both Medicare and Medicaid. Changes to the delivery system should expand access to care coordination in Medicaid and Medicare for people who use long-term services and supports. Legislation introduced in the 110th Congress adding a chronic care coordination benefit is a good place to start. MedPAC recommendations concerning bundled payments and accountable care organizations should be considered. Ultimately legislation that addresses the issues of coordinated and integrated care will improve our system of LTSS and lay the groundwork for broader LTSS reforms in the future.

Certainly, Congress and the new administration should, as part of the health reform process, examine the lessons learned from demonstration projects that integrate the care for the dually eligible. Further integration of care and financing across both programs is needed. This could be done by reforming and reauthorizing Special Needs Plans and expanding in some form successful programs like Evercare and the PACE program. Another approach is simply to build on the universal reach of the Medicare program by creating a modest set of LTSS benefits, either by clarifying the home-bound rule or perhaps by phasing out the two-year waiting period for people with disabilities under the age of 65. These kinds of measures would relieve some of the fiscal pressure on states and what many have termed a fundamental disconnect in Medicare as a program for seniors and people with disabilities: that its benefit package does not include LTSS (Crowley, 2008).

Second, any discussion of health care reform should include not only expansion of Medicaid eligibility but structural improvements in the program that plays a central role in providing LTSS for people with disabilities and chronic care needs. Congress could take immediate steps to increase access to consumer-directed home care by amending the recently created 1915(i) state plan option, expanding the number of services allowed and easing eligibility requirements to make them consistent with eligibility limits in Medicaid waivers. This could be done at fairly low cost (CBO estimates are \$2.7 billion over 5 years and \$8.1 billion over 10 years). Such a change would also be an affordable and important first step toward the ultimate goal of ending Medicaid's institutional bias. Other options for improving Medicaid include expanding the federal matching payment for HCBS to help states reallocate resources toward the kind of LTSS that consumers prefer.

Role of Social Insurance

Where does social insurance fit into the current political environment? There is a broad consensus among advocates and academics that our system of long-term services and supports must, out of sheer political and economic necessity, continue to be a mix of private and public resources. Nevertheless, there are long time observers who feel we have broad agreement on the need for a more assertive federal government role in helping individuals with catastrophically high costs (Jennings and Dawe, 2006). Whether it is health savings accounts or Medicare Part D, there appears to be a broadly accepted argument that public resources are justified for individuals with these kinds of health care needs. As with universal health insurance and long-term care, there was a sense among experts on the NASI panel that agreement over catastrophic care could lay the groundwork for a broader consensus on social insurance.

Critical political questions remain unanswered. Will advocates for both health care reform and for LTSS reform accept anything less than total reform? Advocacy groups have their legislative priorities, but historically, the second choice for most of them has been to do nothing – what one panelist described as the "yes-but" syndrome; LTSS advocates gave the Clinton plan only mild

support despite the fact that the proposal would have transformed our current system and given millions of people home and community-based alternatives to institutions.

The issue this time around is whether stakeholders can make a virtue out of their second-favorite choice, one panelist noted. There are likely to be proposals that increase access to Medicaid HCBS and improve Medicaid-Medicare integration, but that don't provide an alternative to what is fundamentally a means-tested system of LTSS. The question is whether the hunger for change – in terms of unmet need and the vulnerability to impoverishment that our current system creates – produces a willingness to compromise around meaningful incremental reform. If creating a social insurance-based system is the Holy Grail of LTSS reform, then we will surely fail to make any progress for quite a while. But if policymakers and interest groups adopt a pragmatic strategy that blurs the lines between LTSS and health care, we have an opportunity to secure incremental reforms that improve the way Medicaid and Medicare operate for people with disabilities.

This is not to say we should give up on comprehensive reform focused on financing. Progress on comprehensive LTSS reform will only come if there is political pressure and public education about the options. "There must be a cost to politicians who support the *status quo*; doing nothing is a policy choice that has consequences for people ill-served by the current system," noted Ron Pollack, Executive Director of Families USA. "Policymakers today can fail to make substantial progress in reform of our LTSS system without fear of retribution from voters," he said. We must have a strategy that pockets the incremental gains available today, that holds policymakers accountable and that aims higher.

Endnotes

- LTSS encompasses a wide array of medical, social, personal, and supportive and specialized housing services needed by individuals who have lost some capacity for self-care because of a chronic illness or disabling condition. LTSS are needed when a chronic condition, trauma, or illness limits a person's ability to carry out basic self-care tasks, called activities of daily living (ADLs), such as bathing, dressing or eating, or instrumental activities of daily living (IADLs) such as household chores, meal preparation, or managing money. LTSS often involves the most intimate aspects of people's lives—what and when they eat, personal hygiene, getting dressed, and using the bathroom. Other less personal LTSS needs may involve household tasks such as preparing meals or using the telephone (Family Caregiver Alliance 2008).
- ² The U.S. Census Bureau estimates the current population of at least 300 million (U.S. Census Bureau, 2008). Other recent data shows 59 million people eligible for Medicaid (Kaiser Family Foundation, 2008a), and approximately 10 million people with private long-term care insurance policies (Feder, Komisar, and Friedland, 2007). If we assume that individuals who are Medicaid eligible have their LTSS needs covered and that current private insurance plans remain in force, then there are somewhere in the neighborhood of 230 million people who are uninsured when it comes to their potential long-term care needs.
- Health care emerged early on as one of the top issues for voters in the 2008 presidential election, after the economy and the war in Iraq (Kaiser Family Foundation, 2008b). The general importance of health care in this election has been documented by numerous polls: CNN June 26-29, 2008; Time June 18-28, 2008; USA Today/Gallup June 15-19, 2008; NBC News/Wall Street Journal June 6-9, 2008; Diageo/Hotline June 4-5, 2008; CBS May 30-June 3, 2008; Pew Research Center May 21-25, 2008; ABC News/Washington Post May 8-11, 2008; LA Times/Bloomberg May 1-8, 2008; CBS News/New York Times, April 25-29, 2008; Gallup March 6-9, 2008; Pew Research Center February 20-24, 2008; Fortune Magazine January 14-16, 2008 (PollingReport.com, 2008). While the economy was by far the most important issue to voters during the last three months of the race, CNN exit polls show that health care came in tied for third (with terrorism) and right behind the war in Iraq. http://www.cnn.com/2008/POLITICS/11/04/exit.polls/.
- ⁴ Polls suggest that people generally prefer in-home care to nursing homes; 75 percent (Genworth Financial, 2007) to 85 percent (Moore and Kaiser, 2008) of those surveyed conveyed such a preference. However, apparently many do not realize that Medicare and most health insurance plans do not cover home health aides (Genworth Financial, 2007).
- ⁵ "Health Security Act of 1993", S. 1775, HR 3600 103 Cong 1st sess. (1993).
- ⁶ "The Medicare Long-Term Home Care Catastrophic Protection Act of 1987," HR 2762, 100 Cong. 1st sess. (1987).
- ⁷"Life Care, Long-Term Care Protection Act," S. 2163, 101 Cong. 2nd sess. (1990).
- ⁸ "The Long Term Care Assistance Act of 1988," S. 2305, 100 Cong. 2nd sess. (1988).
- ⁹Stark: "Chronic-Care Medicare Long Term Care Coverage Act," HR 5393, 100 Cong. 2nd sess. (1988) and Waxman: "Elder-Care Long Term Care Protection," HR 5320, 100 Cong. 2nd sess. (1988).
- ¹⁰"Community Living Assistance Services and Supports," S. 1951, 109th Cong. 1st sess. (2005)
- ¹¹ A medical home is "a source of usual care selected by the patient (such as a large or small medical group, a single practitioner, a community health center, or a hospital outpatient clinic). The medical home should function as the central point for coordinating care around the patient's needs and preferences. The medical home should also coordinate between all of the various team members, which include the patient, family members, other caregivers, primary care providers, specialists, other health care services (public and private), and non-clinical services as needed and desired by the patient" (National Quality Forum, 2006).
- ¹²"Geriatric Assessment and Chronic Care Coordination Act of 2007", S. 1340/HR 2244, 110th Cong. 1st sess. (2007).

References

- Ambinder, Marc. 2008. *Obama's First 100 Days*, The Atlantic.com. Accessed at: http://marcambinder.theatlantic.com/archives/2008/08/the_big_domestic_policy_goal.ph p on 7/16/2008.
- American Association of Homes and Services for the Aging. 2006. *Financing Long-Term Care:* A Framework for America. Washington, DC.
- Anderson, Gerard. 2005. *Coping With Multiple Chronic Conditions*. Accessed at: http://www.jhsph.edu/publichealthnews/press_releases/2005/anderson_chronic_care.html on 7/30/2008.
- Burke, Sheila P, Judith Feder, and Paul N. Van de Water (eds.). 2005. *Developing a Better Long-Term Care Policy: A Vision and Strategy for America's Future*, National Academy of Social Insurance. Washington, DC.
- Campbell, Andrea L. and Kimberly J. Morgan. 2005. *Federalism and the Politics of Old-Age Care in Germany and the United States*. Sage Publications.
- Citizens For Long Term Care. 2001. *Defining Common Ground: Long Term Care Financing Reform in 2001*. Washington, DC.
- Crowley, Jeffrey S. 2008. *Improving Health Coverage for Americans with Disabilities: Policy Options for the President-elect and the 111th Congress.* O'Neil Institute for National and Global Health, Georgetown University, Washington, DC.
- Duhigg, Charles. 2007. *At Many Homes, More Profit and Less Nursing*. The New York Times. New York, NY.
- Family Caregiver Alliance. 2008. *Selected Long-Term Care Statistics*. National Center on Caregiving. Accessible at: http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodejd=440.
- Feder, Judith, Harriet L. Komisar and Robert B. Friedland. 2007. *Long-Term Care Financing: Policy Options for the Future*. Long-Term Care Financing Project, Georgetown University, Washington, DC.
- Genworth Financial. 2007. Long-Term Care National Poll. New York, NY.
- Gibson, Mary Jo. 2003. *Beyond 50.03: A Report to the Nation on Independent Living and Disability*. AARP, Washington, DC. Accessed at http://www.aarp.org/research/health/disabilities/aresearch-import-753.html.
- Glied, S, and B. Mahato. 2007. *Analysis of March 2007 Current Population Survey for the Commonwealth Fund*. Accessed at http://www.commonwealthfund.org/chartcartcharts/chartcartcharts_show.htm?doc_id=68 7829&trackTitle=There%20Are%2013%2E7%20Million%20Uninsured%20Young%20 Adults%2C%20Ages%2019%9629%2C%20Almost%2030%20Percent%20of%20Nonel derly%20Uninsured%2C%202006&trackLable=email%2Dfriend%5FCharts on 8/30/2008.
- Goldberg, Lee (Moderator). 2008. Addressing the Invisible Uninsured: Long-Term Care as Part of Health Care Reform (Transcript). National Academy of Social Insurance. Washington, DC.
- Jennings, Christopher and Christopher Dawe. 2006. Long-Term Care: The Forgotten Health Care Challenge. Leading the Way to Broader Reform. Washington, DC.
- Kaiser Family Foundation. 2008a. *Medicaid Fast Facts*. Accessed at: http://facts.kff.org/default.aspx on 7/30/2008.
- Kaiser Family Foundation. 2008b. Kaiser Health Tracking Poll: Election 2008. Washington, DC.
- Moore, Bob and Hans Kaiser. 2008. U.S. Voters and Long-Term Care. Annapolis, MD.
- The National Quality Forum. 2006. NQF Endorsed Definition and Framework for Measuring Care Coordination.

- Pollingreport.com. 2008. *Problems and Priorities*. Accessed at: http://www.pollingreport.com/prioriti.html on 7/16/2008.
- SEIU. 2008. SEIU Members to Politicians: Live up to Your Promises or We Will Hold You Accountable. Accessed at: http://www.seiu.org/media/pressreleases.cfm?pr_id=1662&bSupressLayout=1 on 7/16/2008.
- Stevenson, David. 2008. *Planning for the Future Long-Term Care and the 2008 Election*. The New England Journal of Medicine. Waltham, MA.
- The SCAN Foundation. 2008. Long-Term Care An Essential Element of Health care Reform. Long Beach, CA.
- U.S. Census Bureau. 2008. *Census Bureau Projects Populations of 303.1 Million*. Accessed at http://www.census.gov/Press-Release/www/releases/archives/population/011108.html on 7/16/2008.
- Wiener, Joshua, Carroll Estes, Susan M. Goldenson, and Sheryl Goldberg. 2001. What Happened to Long-Term Care in the Health Reform Debate of 1993-1994? Lessons for the Future. The Milbank Quarterly, Vol. 79, No. 2, Malden, MA.
- Weiner, Joshua M., Laurel H. Illston, Raymond J. Hanley. 1994. *Sharing the Burden: Strategies for Public and Private Long-Term Care Insurance*. The Brookings Institution, Washington DC.
- Yglesias, Matthew. 2008. *150 million is a lot of money*... The Atlantic.com. Accessed at: http://matthewyglesias.theatlantic.com/archives/2008/05/150_million_is_a_lot_of_money.php on 7/16/2008.

Addressing the Invisible Uninsured: Long-Term Care as Part of Health Care Reform? National Academy of Social Insurance Conference Roundtable February 1, 2008

Panelists

Lee Goldberg directs long-term care policy initiatives for the Service Employees International Union, which represents more than a half-million nursing home and home care workers who provide services funded primarily through the Medicaid program. Previously, he served as Press Secretary for the National Committee to Preserve Social Security and Medicare and Assistant Director for Health Policy for United Jewish Communities. A member of the National Academy of Social Insurance since 2006, Goldberg holds a law degree from George Washington University.

Chris Jennings is a more than two decade-long health policy veteran of the White House, Congress and the private sector. He currently serves as president of Jennings Policy Strategies (JPS), Inc., a nationally respected health policy and advocacy consulting firm in Washington, D.C. Prior to founding JPS, Inc., Jennings served in the White House as the Senior Health Care Advisor to President William Jefferson Clinton at the Domestic Policy and National Economic Councils. In 1993 and 1994, he served as the Senior Advisor to the Administrator of the Health Care Financing Administration (now CMS). Prior to joining the Clinton Administration, Jennings served as Committee staff for three United States Senators (Glenn, Melcher, and Pryor) over the course of almost ten years on Capitol Hill. As Deputy Staff Director of the Senate Aging Committee for Chairman David Pryor (D-AR), he staffed the Senator before the Finance Committee and the "Pepper Commission."

Stephen McConnell is Ageing Program Policy and Advocacy Program Executive at Atlantic Philanthropies. At the time of this roundtable event, McConnell was Senior Vice President for Advocacy and Public Policy at the Alzheimer's Association. In addition to his public policy role, he directed the Program Services Division and, in 2002, served as the Association's interim President and CEO. Before joining the Alzheimer's Association, McConnell spent seven years on Capitol Hill, as staff director of the U.S. Senate Special Committee on Aging under the chairmanship of Sen. John Heinz, and as a professional staff member for the U.S. House of Representatives, Select Committee on Aging, under the chairmanship of Rep. Claude Pepper. He also directed a national issue campaign on long term care during the 1988 Presidential election cycle. A founding member of the National Academy of Social Insurance, McConnell received his Ph.D. in sociology from the University of Southern California.

Ron Pollack is Executive Director of Families USA. Prior to his current position at Families USA, Pollack was the Dean of the Antioch School of Law. In 1997, Pollack was appointed by President Clinton as the sole consumer representative on the Presidential Advisory Commission on Consumer Protection and Quality in the Health Care Industry. In that capacity, Pollack helped prepare the Patients' Bill of Rights that has been enacted by many state legislatures. He was also the Founding Executive Director of the Food Research and Action Center (FRAC). A founding member of the National Academy of Social Insurance, Pollack received his law degree from New York University.

Robyn I. Stone is the Executive Director of the Institute for the Future of Aging Services, housed within the American Association of Homes and Services for the Aging. She is a noted researcher

and internationally recognized authority on health care and aging policy. Stone has held senior research and policy positions in both the U.S. government and the private sector. She served in the U.S. Department of Health and Human Services as Deputy Assistant Secretary for Disability, Aging and Long-term Care Policy from 1993 through 1996, and as Assistant Secretary for Aging in 1997. In the 1980s and early 1990s, she was a senior researcher at the National Center for Health Services Research, and at Project HOPE's Center for Health Affairs. Stone has been on the staff of two important national task forces, the 1989 Bipartisan Commission on Comprehensive Health Care (the Pepper Commission) and the 1993 Clinton Administration Task Force on Health Care Reform. A member of the National Academy of Social Insurance since 1993, Stone received her doctorate in public health from the University of California, Berkeley.

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