













Most health policy experts now agree that the existing health care delivery system will have to undergo major changes in order to effectively address the ills of the existing system. Strategic investments in the system's underlying infrastructure will be required to improve the cost effectiveness of services, including a substantial infusion of new funds to modernize management information systems, improve system-wide coordination, ensure evidence-based decision-making and improve the quality and consistency of health services. Largely overlooked in the national health care debate thus far, however, is that similar steps are necessary to improve the productivity of long-term service and support systems in the United States.

*As the debate surrounding the modernization of health delivery systems unfolds, little attention has been focused on the parallel need to strengthen the infrastructure of long-term service delivery systems*

## Employing Efficient and Sustainable Financing Methods

Paradoxically, curbing the rate of growth in health care outlays has emerged as both the most compelling argument for health policy reform as well as the most formidable barrier to enacting such reforms. Unless assertive steps are taken soon to slow the rate of growth in health spending, most economists agree the U.S. economy will spin out of control. In its latest budget projections, the Congressional Budget Office (CBO) concludes that “if current laws do not change:

federal spending on Medicare and Medicaid combined will grow from roughly 5 percent of GDP today to almost 10 percent by 2035 ... and to more than 17 percent by 2080... That projection means that in 2080, without changes in policy, the federal government would be spending almost as much, as a share of the economy, on just two major health care programs as it spent on all of its programs and services in recent years.<sup>20</sup>

At a June 23rd White House press conference, President

Obama stressed the importance of controlling health care costs when he said “... the status quo is unsustainable and unacceptable...” Any reforms enacted by Congress, he emphasized, must “... bring down the crushing cost of health care.”<sup>21</sup> Yet, Congress and the Administration thus far have been unable to reach agreement on how to finance the enormous front-end cost of reforming the nation's health care system. Advocates of health reform contend that system-wide costs can be reduced substantially by emphasizing prevention and wellness, improving health information systems, rooting out fraudulent billing practices, promoting the use of evidence-based practices and designing payment systems which reward cost-effectiveness.

But, CBO, the ultimate arbiter of Congressional cost estimates, has assigned low savings estimates to most of these reforms, arguing that evidence of their effectiveness in reducing costs is weak or non-existent.

As a result, Congress faces the far less politically palatable task of slashing existing Medicare and Medicaid spending and/or raising new revenues to cover the estimated \$1 trillion to \$1.7 trillion price tag of health reform over the next 10 years. The Obama Administration has proposed a series of changes in Medicare and Medicaid policy which it argues could save between \$600 and \$650 billion over the next ten years; however, there is strong opposition to many elements of the Administration's savings plan. Various stakeholders also are opposed to taxing employees for at least a portion of the value of employer-paid health insurance, lowering health care tax deductions for wealthy individuals and families and adding federal excise taxes on alcoholic and sugary beverages. Whether Congress is able to cobble together an acceptable financing plan has emerged as a “make or break” test of health reform legislation. At the moment, the outcome remains in doubt, although it seems increasingly likely that a number of highly touted proposals will end up “on the cutting room floor” if reform costs are to be lowered to a level that will attract majority support for the legislation in Congress. Long-term services reforms are likely to be among the casualties of the current process of working out an acceptable financing plan.

After receiving CBO's cost estimates on a preliminary reform plan, for example, key members of the Senate Finance Committee went back to the drawing board and trimmed the ten-year cost of the plan from around \$1.6 trillion to a little less than one trillion dollars, mainly by reducing premium subsidies for middle class families and eliminating non-core features of the committee's original plan. The contents of the committee's revised bill will not be known until the panel marks up the measure in July, but it is expected to be less far-reaching than the committee's original proposal. Even in the initial version, the long-term services proposals consisted mainly of incremental changes in existing laws (see *Policy Insights Bulletin* No. 2009-2 for a summary of the proposal under consideration).

A similar cost containment exercise was underway within the Senate Health, Education, Labor and Pensions (HELP) Committee after preliminary CBO cost estimates generated strong opposition among Republicans and conservative Democrats and raised doubts about whether major features of the HELP plan would be incorporated in the final, combined health reform measure that goes to the Senate floor. The HELP committee's draft bill,

unlike the Finance Committee's draft, would establish a new, worker-financed disability insurance program designed to help beneficiaries pay for long-term services and supports. The disability insurance program, however, may survive the cut since CBO estimates that it would generate \$58 billion in new revenue over ten years and these revenues would be

available to offset other health reform costs.<sup>22</sup> But critics of the proposed program point out that the new revenues result mainly from a stipulation that no participant will receive benefits until he or she has paid into the insurance trust fund for a minimum of five years. They are concerned about the longer range financial viability of the program and argue that the

government could end up mired in another expensive bailout the nation can ill-afford. Moreover, as pointed out in *Policy Insights Bulletin* No. 2009-2, while the proposed disability insurance program would assist individuals disabled later in life to pay for needed long-term services, it would be of little or no assistance to individuals with lifelong disabilities, many of whom would be unable to work and make the required contributions to the fund.

Democratic leaders of the House of Representatives unveiled a draft health reform measure on June 19, 2009 that was developed jointly by the majority members of three House committees (Energy and Commerce; Education and Labor; and Ways and Means). The draft legislation did not include a financing plan but, given the wide ranging scope of the measure and the comparative high subsidy levels it included, health economists say that implementation costs would be high – probably in the range of \$1.6-\$2.0 trillion over ten years. Yet, the 850 page draft bill is almost devoid of provisions aimed at improving access to long-term services.

*The final contents of health reform legislation will be strongly influenced by efforts to curb the growth in health care outlays and avoid adding to the burgeoning federal debt. Long-term services reforms may be among the casualties.*

In summary, as Congress begins the process of fashioning a detailed health reform measure, the outcome is likely to be shaped largely by two factors: (a) the need to curb the growth in health expenditures; and (b) the front-end costs required to institute desired health system reforms and the sources tapped to finance these costs.

If health care costs continue to increase by 2 to 3 percentage points above the general inflation rate, as they have over the past three decades, any reform plan will fail, throwing the overall national economy into a dangerous tailspin. There is no shortage of proposals for improving the cost-effectiveness of the existing health

care system; and, in many cases, we have working models of how non-essential costs can be squeezed out of existing health care delivery systems without compromising – and in some cases even improving – service accessibility and quality. The problem lies in instituting such reforms on a massive, nationwide scale and dealing with the unintended consequences that may

(and probably will) result. Some reform proponents have begun to argue that it will be necessary to build a fail-safe mechanism into the legislation where automatic reductions in provider payments and consumer subsidies are triggered if the restructured care delivery system fails to meet prescribed cost-containment goals.<sup>23</sup>

Early CBO cost estimates have created “sticker shock” in Congress by underscoring the huge costs associated with reforming the American health care system. Now that both President Obama and Congressional leaders have faced up to the reality that all reforms will have to be fully financed to avoid a financial meltdown in the nation’s debt-laden economy, the question is: can the Administration and Congress reach agreement on the overall scope of the plan and the mix of funds required to implement it. Plenty of alternatives are available, ranging from deeper spending cuts to new revenue sources and tax offsets. But, each potential source of savings or new revenue has its own constituency that will argue vehemently for tapping other sources. A successful plan – if it can be developed – is likely to involve some sacrifices on the part of all key stakeholders, while at the same time managing to avoid ruinous effects on the interests of any given constituency. Some observers have begun to refer to this approach as a Goldilocks strategy.

## Conclusion

For decades long-term services have been the step child of health care policy. Authorized primarily under health statutes, these services fall under the medical care policy umbrella, but in practice exist outside the mainstream of the American health care system – an orphan with only the most tenuous ties to medical care. Except for the relatively small portion of the American public who require such services and supports at any given point in time, long-term services are far removed from the day-to-day consciousness of most Americans. Changes in government long-term services policies usually have been tucked into major pieces of health legislation, almost as an after-thought. It seems unlikely given developments to date that this pattern will change

during the current national health care reform debate. In fact, the closer Congress gets to fashioning a health reform strategy the more apparent it becomes that any long-term services provisions which are included in the authorizing legislation will be primarily incremental in nature. The one possible exception to this rule could be the creation of a disability insurance program that helps qualified beneficiaries meet the out-of-pocket costs of

*For decades long-term services has functioned as the step child of health care policy and there is no compelling reason to believe the situation will be different this time around.*

long-term care services and supports. But, even here, the odds are that Congress will end up creating a time-limited demonstration authority rather than a full-blown new insurance program due to concerns about the long-range financial viability of such a program.

The failure of Congress to design bold new solutions to the growing crisis in long-term services undoubtedly will be a disappointment to many reform advocates. But, it might not be the worst possible outcome given the fact that: (a) existing authorities under federal Medicaid law to expand and improve long-term services will remain in place and may even be strengthened to some extent; and (b) the major, over-riding questions surrounding the basic design features of an improved long-term service system haven’t been fully debated, much less resolved. Among these questions are:

- Should the current relationship between the federal government and the states in designing, financing and administering long-term services and supports for persons with severe, chronic disabilities be altered in any fundamental ways; and, if so, how?
- Should the present balance between government assistance and individual and family responsibility be recalibrated and, if so, in what ways?
- Should direct cash assistance vs. government-financed services play a larger or more confined role in helping to meet the ongoing support needs of Americans with severe, chronic disabilities?
- How do we design a system of financing and service

delivering that both honors the differences among various long-term services sub-populations while at the same time recognizing the commonality of needs and aspirations among such persons (see *Policy Insights Bulletin* No. 2009-2 for an extended discussion of this issue)?

Some will argue that there will be opportunities to address the glaring weaknesses and discontinuities in long-term service delivery systems once major health reform legislation is enacted by Congress. But, history suggests that it may take years for the American public and its elected representatives to turn their attention to fixing long-term services policy. In the late 1980s, for example, it appeared that pressure was building to sharply expand home health benefits under the Medicare program; but, when the House of Representatives failed to enact a bill (H.R. 3436) sponsored by Representative Claude Pepper (D-FL) in

1988, the issue soon dropped off the Congressional radar screen never to resurface as a politically viable option.

Hopefully, long-term services policy will be a front-and-center issue considerably before the late 2020s. In the meantime, developmental disabilities stakeholders will have to muddle through with current policy tools, perhaps supplemented by a few useful statutory and regulatory tweaks along the way. The next few fiscal years are likely to be a hostile environment for program innovations and expansions given the devastating effects the current economic recession is having on state budgets. But, eventually the economy is going to turn around – if not this fiscal year then the following year or the year after that – and DD stakeholders must be prepared to exploit the available opportunities in Medicaid and other government policies. ♦

*Reader comments and questions are welcome, including suggestions regarding future bulletin topics. Direct your comments or suggestions to Bob Gettings at [rgettings@wildblue.net](mailto:rgettings@wildblue.net).*

## End Notes

<sup>1</sup> U.S. Census Bureau, “Income, Poverty and Health Insurance Coverage in the United States: 2007,” U.S. Census Bureau, <http://www.census.gov/prod/2008pubs/p60-235.pdf>.

<sup>2</sup> Rita Mangione-Smith, et al., “The Quality of Ambulatory Care Delivered to Children in the United States,” *New England Journal of Medicine*, No. 357 (October 11, 2007), 1515-23.

<sup>3</sup> Tumlinson, Anne, et al., “Closing the Long-Term Care Funding Gap: The Challenge of Private Long-Term Care Insurance,” “The Kaiser Commission on Medicaid and the Uninsured, June 2009, p. 1. Available online at <http://www.kff.org/insurance/kcmu060309pkg.cfm>.

<sup>4</sup> In states that agree to coordinate Medicaid eligibility with private long-term care insurance coverage (the so-called “partnership” states), the applicable provisions of the Deficit Reduction Act of 2005 (P.L. 109-171) exempt qualifying policy holders from the Medicaid asset test and, thus, qualify for Title XIX benefits without spending down all of their assets. The recent Avalere/Kaiser Commission study found that at least 30 states had adopted the partnership program and predicted soon all private LTC insurance policies in partnership state will qualify for the Medicaid assets exemption.

<sup>5</sup> Tumlinson, *Ibid*, page 14.

<sup>6</sup> See *Policy Insights Bulletin* No. 09-02, entitled “Will National Health Reform Help Individuals with Developmental Disabilities?” for a more in-depth commentary on the impact of the proposed CLASS Act on persons with intellectual and developmental disabilities. Available online at <http://www.nlcdd.org/insights/>.

<sup>7</sup> For a commentary on the likely impact of the CLASS legislation on services and supports to persons with developmental disabilities, see *Policy Insights Bulletin* No. 09-02, entitled “Will National Health Reform Help Individuals with Developmental Disabilities,” pp. 7-8.

**End Notes** *continued...*

- <sup>8</sup> Diane Rowland, “Filling in the Long-Term Care Gaps,” a statement of testimony before the Senate Special Committee on Aging, June 3, 2009, p. 6.
- <sup>9</sup> Ric Zaharia and Charles Moseley, “State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants,” Rutgers Center for State Health Policy, May 2008.
- <sup>10</sup> See, for example, the findings of a report recently released by the Virginia Joint Legislative Audit and Review Commission, entitled *Assessment of Services for Virginians with Autism Spectrum Disorders*, June 2008. Available online at <http://jlarc.state.va.us/meetings/June09/Autism.pdf>.
- <sup>11</sup> K. Charlie Lakin, Robert Prouty, Kathryn Alba and Naomi Scott, “Twenty-Five Years of Medicaid Home and Community Based Services (HCBS): Significant Milestones Reached in 2007,” in *Intellectual and Developmental Disabilities*, Vol. 46, No. 4 (August 2008), pp. 325-330.
- <sup>12</sup> Sean Keehan, et al., “Health Spending Projections Through 2017: The Baby Boom Generation is Coming to Medicare,” *Health Affairs*, 27, No. 2 (2008): pp. 145-155.
- <sup>13</sup> Peter Orszag, “The Budget and Economic Outlook: Fiscal Years 2008-2018,” testimony presented to the U.S. Senate Budget Committee, January 24, 2008.
- <sup>14</sup> Prevailing nomenclature differs from state to state, with terms such as “service coordination” and “supports coordination” used increasingly to describe the constellation of activities traditionally referred to as “case management.” The terms “case management” and “service coordination” are used interchangeably in the present discussion.
- <sup>15</sup> Robin Cooper, “Survey of State Case Management Policies and Practices,” NASDDDS Technical Report, National Association of State Directors of Developmental Disabilities Services: Alexandria, Va., August 31, 2006, p. 8.
- <sup>16</sup> U. S. General Accounting Office, *Federal Oversight of Growing Medicaid Home and Community-based Waivers Should be Strengthened*, GAO-03-576, June 2003.
- <sup>17</sup> For an explanation of the statutory and regulatory basis of enhanced FFP claims to develop and improve MMIS capabilities – as well as a summary of the experiences of states which have attempted to add specialized I/DD components to their MMISs -- see “Claiming Federal Reimbursement for Management Information System Improvements,” *Policy Analysis Bulletin* No. 01-2003, National Association of State Directors of Developmental Disabilities Services: Alexandria, Va., August 25, 2003.
- <sup>18</sup> Stancliffe, Roger J. and K. Charlie Lakin, “Context and Issues in Research on Expenditures and Outcomes of Community Services,” in *Costs and Outcomes of Community Services for People with Developmental Disabilities*, Roger J. Stancliffe and K. Charlie Lakin (editors). Paul H. Brookes Publishing Co.: Baltimore, Md. 2005, pp. 1-22.
- <sup>19</sup> Federal Coordinating Council for Comparative Effectiveness Research, *Report to the President and Congress*, U.S. Department of Health and Human Services: Washington, D.C., June 30, 2009. Available online at <http://www.hhs.gov/recovery/programs/cer/cerannualrpt.pdf>.
- <sup>20</sup> Congressional Budget Office, *The Long-Term Budget Outlook*, U.S. Congress: Washington, D.C., June 2009, page xi.
- <sup>21</sup> Transcript of Presidential press conference, June 23, 2009, Office of the Press Secretary, White House: Washington, D.C.
- <sup>22</sup> “Democrats’ Long-Term Care Insurance Plan Would Produce \$58 Billion in Revenue: CBO,” *CQ Politics Online*, June 26, 2009.
- <sup>23</sup> David M. Cutler and Judy Feder, “Financing Health Care Reform: A Plan to Ensure the Cost of Reform is Budget Neutral,” Center for American Progress, June 2009. Available online at [http://www.americanprogress.org/issues/2009/06/health\\_financing.html](http://www.americanprogress.org/issues/2009/06/health_financing.html).

# The National Leadership Consortium

on Developmental Disabilities

## The National Leadership Consortium on Developmental Disabilities

Center for Disabilities Studies

461 Wyoming Road

Newark, DE 19716

Tel 302-831-8536

Fax 302-831-7220

Email [nlcddonline@udel.edu](mailto:nlcddonline@udel.edu)

Sponsorship of this bulletin series is made possible by a generous grant from:



### **Liberty Healthcare**

*Expertise, experience, and proven programs and support  
for people with intellectual and developmental disabilities.*

Contact Pat Donnelly at [PatD@Libertyhealth.com](mailto:PatD@Libertyhealth.com)

or (800) 331-7122 x 140