

# Policy Insights

## *The Future of Long-Term Services as Viewed through the Prism of Health Reform Legislation*

*As President Obama and Congress forge legislative solutions to the current health care crisis, are they overlooking equally compelling arguments for reforming long-term services needed by some ten million Americans with severe, chronic disabilities? This second in a two-part series of bulletins dealing with the impact of health reform legislation on persons with lifelong disabilities explores the similarities and differences in underlying strategies for restructuring health care and long-term services policies nationwide.*

The National Leadership Consortium on Developmental Disabilities is a project of the University of Delaware's Center for Disabilities Studies, conducted in collaboration with the Department of Human Development and Family Studies. This is the first in a series of bulletins prepared by Robert M. Gettings who for nearly four decades led the National Association of State Directors of Developmental Disabilities Services (NASDDDS). He is one of the nation's leading experts on public policy as it impacts on people with intellectual and developmental disabilities. The series is made possible through funding from the Liberty Healthcare Corporation. Liberty Healthcare exercises no editorial control over the content of these bulletins.



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Months before President Obama designated the passage of national health reform legislation as his top domestic priority efforts were underway both within and outside of

Congress to forge agreement on the principal elements of a reform plan. The results of these deliberations are now being translated into specific legislative proposals that will be the subject of extensive debate and, no doubt, hard-fought battles over the next few months. Given the complexities of the issues involved and the competing forces poised to influence the outcome, the precise form the final legislation might take remains in doubt. Yet, despite numerous failed attempts in the past, it appears increasingly likely that Congress will enact major changes in health care policy before the end of the year. As President Obama recently put it, this time the "stars appear to be aligned." Indeed, while many critical issues have yet to be resolved, the principal elements of a health reform strategy are beginning to emerge.

Far less evident is how long-term services would be altered as a result of the passage of a national health reform measure. An earlier bulletin in the "Policy Insights" series explored the implications of possible long-term services reforms, with particular emphasis on the likely effects such proposed policy changes would have on the provision of Medicaid-funded long-term services to children and adults with developmental disabilities (<http://www.nlcdd.org/insights/>). In this bulletin, we turn our attention to the underlying rationale for restructuring the American health care system and examine whether the same or different arguments apply to revamping national long-term services policies. Our examination will focus on the principal elements of a health reform strategy and ask whether parallels exist within the long-term services policy arena.

### **Achieving Universal Access to Services**

One of the perennial criticisms of the American health care system is that too many Americans have no regular access to the health care services. An estimated 46 million individuals are uninsured – up from 38 million in 2000 – and another 25 million are under-insured.<sup>1</sup> The cost of caring for the

uninsured is borne largely by those with insurance. Health care providers typically charge more for their services in order to cover the cost of uncompensated care and these costs in turn are reflected in higher insurance premiums. As a result, increasingly families struggle to keep pace with the growing out-of-pocket costs of medical care. Furthermore, today many Americans forego needed medical care either because they lack health insurance or have inadequate coverage. Studies indicate that adults receive prescribed medical care only about 55 percent of the time. And, the rate among children is worse.<sup>2</sup> Advocates of health care reform contend that guaranteeing all Americans access to health care would sharply reduce the number of people who forgo needed care and, as a result, eventually need more expensive interventions. Universal coverage also would end the practice of denying insurance coverage to individuals with pre-existing health conditions and prevent individuals and families from losing essential health coverage when they change jobs.

Achieving universal access to services within the long-term services sector poses different challenges. All Americans face the risk of life-altering disabilities, but only a small percentage of health consumers – a little over 3 percent – require long-term services and supports at a given point in time; and, importantly, few “temporarily able-bodied” adults thus far have been willing or able to insure themselves against the risks of severe physical or cognitive disabilities later in life. A recent study conducted by the Kaiser Family Foundation (KFF) in conjunction with Avalere Health, LLC estimated that six to seven million Americans carry private long-term care insurance policies and during 2007 these policies paid \$4 billion in claims on behalf of covered beneficiaries. These payments made up only a tiny fraction of the estimated \$200 billion expended that year on long-term services.<sup>3</sup>

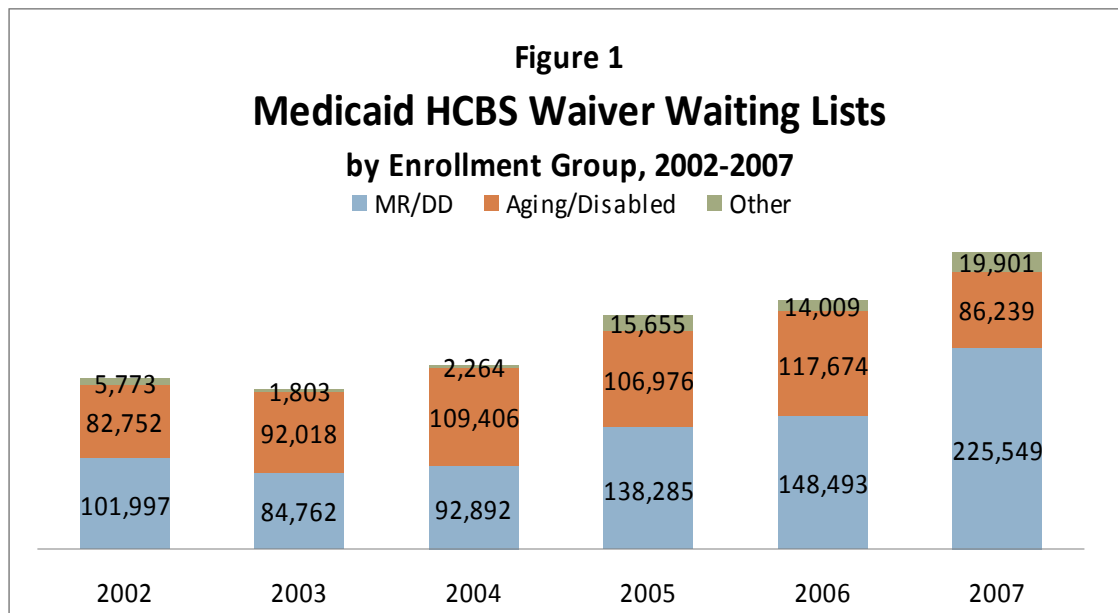
Congress has taken steps in recent years to encourage the purchase of long-term care insurance by, first,

*All Americans face the risk of life-altering disabilities, but only a small percentage require long-term services at any point in time*

subjecting premium payments on such policies to favorable tax treatment and, more recently, exempting policy holders from the Medicaid assets test as long as the policy meets certain federal and state guidelines.<sup>4</sup> As a result, the percentage of elders with long-term care insurance is likely to increase in the years ahead. But, as the authors of the Avalere/KKF study concluded, “it appears unlikely that the long-term care insurance market will experience the kind of dramatic growth necessary to shift a substantial portion of the long-term care financing burden from Medicaid and individuals to private insurance.”<sup>5</sup> In the context of the present analysis, the more important point is that private LTC insurance will have little or no impact on financing long-term supports for younger individuals with disabilities, especially persons with lifelong disabilities. Nor can we anticipate that worker-financed LTC savings accounts, along the lines of the plan outlined in the Community Living Assistance Services and Supports (CLASS) Act,<sup>6</sup> will reduce system-wide reliance on publicly financed long-term services and supports, at least with respect to persons with disabilities of early onset.<sup>7</sup> Efforts to expand access to long-term services and supports, therefore, must focus primarily on modifying public benefit programs, rather than altering the dynamics of insurance markets.

Still the long-term service system is plagued by its own version of the “haves” and the “have nots,” except the gap in services is measured in terms of the number of persons waiting for services rather than the number of uninsured or under-insured persons. The Kaiser Commission on Medicaid and the Uninsured reports that 331,000 individuals were on waiting lists for Medicaid-funded home and community-based (HCB) waiver services in 2007.<sup>8</sup> As shown in Figure 1 on the following page, persons with intellectual and developmental disabilities made up over two-thirds (68%) of all individuals waiting for HCB services in 2007. And, both the number and the proportion of persons on I/DD waiting lists has grown rapidly in recent years despite a steady increase in the number of persons with intellectual and developmental disabilities enrolled in HCBS waiver programs.

Waiting list data generally under-reports the true universe of needs because persons who are ineligible to receive Medicaid services are not included, either because they (or, in the case of children, their families)



**NOTE:** Other categories include waivers serving children, persons with HIV/AIDS, mental illnesses, traumatic brain injuries and spinal cord injuries.

**SOURCE:** Kaiser Commission on Medicaid and the Uninsured, based on an analysis of CMS Form 272 data completed by researchers at the University of California at San Francisco.

do not meet the state’s financial needs standards or its test of a qualifying disability. Eligibility for Medicaid-funded HCB waiver services is linked to a stipulation that, in the absence of home and community-based services, the applicant would require care in a Medicaid-certified institution (typically an ICF/MR-certified facility in the case of a person with an intellectual or developmental disability). Many individuals with less severe intellectual and developmental disabilities who nonetheless need long-term supports do not qualify for Medicaid HCB waiver services. Moreover, as evidenced by the findings of a 2008 eligibility analysis released by the Rutgers Center for State Health Policy, access to MR/DD services in many states is limited, either by policy or practice, largely to persons who have intellectual disabilities occurring alone or in combination with other emotional, physical, sensory and developmental disabilities.<sup>9</sup> As a result, persons with other developmental disabilities – particularly individuals with autism spectrum disorders – are under-represented in MR/DD waiver programs of many states.<sup>10</sup>

According to statistics compiled by the Rehabilitation Research and Training Center at the University of Minnesota, enrollment in Section 1915(c) waiver programs for persons with intellectual and

developmental disabilities grew from 378,566 in 2002 to 501,489 in 2007.<sup>11</sup> Yet, during this same five-year period, the number of persons on waiting lists for I/DD waiver services more than doubled, growing from 101,997 to 225,549 (see Figure 2 on page 4).

*Enrollment in MR/DD waiver services would have had to be increased by 45% in 2007 to meet current service demands*

Even if we were to assume, however, that existing waiting list statistics are a fair representation of the universe of need, states would have had to increase overall

enrollments in MR/DD waiver services by 45 percent in order to fully address service demands in 2007. Much like the American health care system, the long-term support system for persons with intellectual and developmental disabilities (as well as parallel systems serving persons with other severe, chronic disabilities) faces a serious shortage of essential services.

Furthermore, as is the case with the current health care

system, a strong emphasis is placed on dealing with the manifestations of severe disabilities once they occur, rather than focusing on prevention and early intervention services.

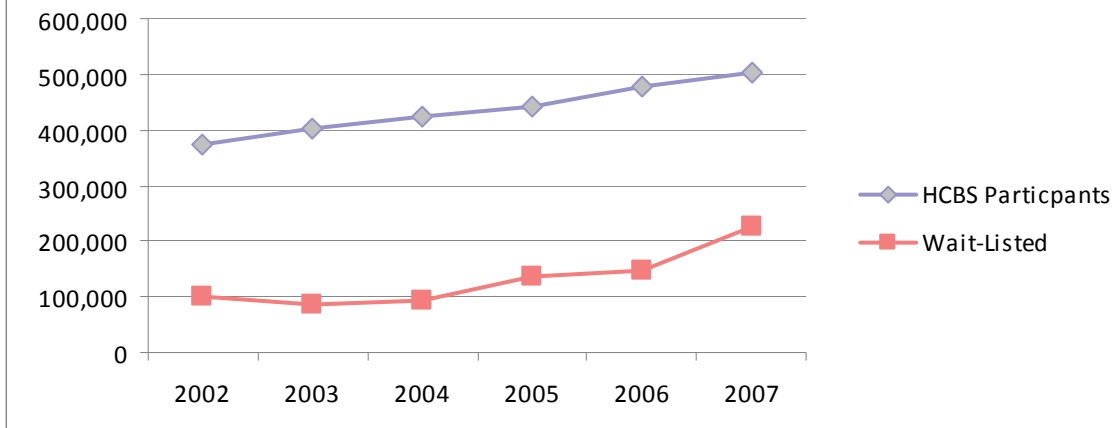
## Improving Health Care Quality and Value

One of the central goals of health reform advocates is to improve the overall cost-effectiveness of health services and thereby place health spending on a more sustainable course in the years ahead. The United States currently spends more than 16 percent of its gross domestic product (GDP) on health care – a much higher share than other industrial nations with high-performing health care systems that provide coverage for everyone. And, by 2017 health expenditures are expected to consume 20 percent of GDP, or \$4.3 trillion annually, unless corrective steps are taken soon.<sup>12</sup> Due to many of the same factors affecting private health care spending, Medicare and Medicaid outlays are projected to increase by 114 percent over the next decade, compared to a 64 percent rise in GDP.<sup>13</sup>

Among the ways in which the Obama Administration and Congressional leaders plan to promote the cost effective delivery of health care services are to:

- Strengthen the role of primary care physicians and enhance the value placed on their work, thus shifting the emphasis of care away from high cost specialists, especially for individuals with chronic health conditions.
- Expand Medicare’s role in testing and implementing the medical home model, in which practitioners are paid for providing comprehensive care management services, and create community health teams in rural areas where the medical home model may not be feasible.
- Expand pay-for-performance and quality reporting initiatives, building off of the existing Medicare hospital pay-for-performance program and Physician Quality Reporting Initiative, with the aim of transitioning to a value-based purchasing model where hospitals and eventually other health providers (e.g., nursing homes and home health agencies) are rewarded based on their performance rather than on the units of service delivered.
- Improve coordination and accountability by eliminating barriers between key system actors (e.g., providing enhanced coordination between community physicians and hospitals in tracking

**Figure 2**  
**MR/DD Waiver Participants Compared to Wait-Listed**  
**Individuals: 2002-2007**



Source: Waiver participation data: Prouty, et al., *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007*, Research and Training on Community Living, Institute on Community Integration/UCEDD, University of Minnesota: Minneapolis, August 2007. Waiting list data: Kaiser Commission on Medicaid and the Uninsured, based on an analysis of CMS 272 data by a research team at the University of California at San Francisco.

patient discharges in order to minimize the number of costly re-admissions).

- Foster collaboration among multiple specialists with the goal of improving patient care and avoiding duplicative and unnecessary tests and interventions. Such initiatives might include bundled payments to hospitals and treating physicians on behalf of a given patient, physician group practice demonstrations, and gain-sharing initiatives involving hospitals and treating physicians.
- Establish Accountable Care Organizations responsible for bringing together health care practitioners across care settings to improve the quality and cost-effectiveness of health care interventions.
- Improve information technology with an emphasis on developing the capability to: (a) track patient care both longitudinally and across multiple health care providers; (b) allow physicians to order medications, lab work and other tests – and access the results – online; (c) file reports on chronic disease registries; and (d) access literature on evidence-based decision-making to guide treatment decisions by physicians and patients. Congress included in the American Recovery and Reinvestment Act (ARRA; P.L. 111-5) \$19.2 billion to stimulate system-wide improvements in health information technology.
- Support comparative effectiveness studies in order to identify the most efficacious health intervention strategies and pinpoint gaps in clinical knowledge which prevents the health care system from consistently delivering the best patient outcomes. The ARRA, as signed into law by President Obama on February 17, 2009, includes \$1.1 billion to underwrite the cost of comparative effectiveness studies.

*Long-term care delivery systems struggle with many of the same issues facing acute health care systems:*

- *Lack of effective service coordination*
- *Inadequate quality monitoring/ enforcement*
- *Outmoded information systems*
- *Lack of comparative effectiveness studies of alternative interventions*

Long-term care delivery systems struggle with many of the same issues facing acute health care systems – i.e., a lack of effective service coordination, inadequate quality monitoring and enforcement, outmoded information systems and data analysis capabilities, plus an absence of well-documented studies of the comparative effectiveness of alternative intervention strategies. Let's briefly examine how these deficiencies manifest themselves in long-term services systems.

For decades, service (care) coordination has been widely viewed as an essential component of any

effective long-term care delivery system. Yet, in many systems service coordination is under-resourced and marginally effective at best in orchestrating the delivery of services and supports. The tradition of a robust, decentralized case management system<sup>14</sup> is especially strong in the I/DD sector, with existing systems in many states dating back to the 1960s and early 1970s. Yet, for a variety of reasons, I/DD case management systems rarely live up to the lofty expectations that have been established and are the target of widespread criticism in many states. Based on a 2006 survey of member state agencies, the National Association of State

Directors of Developmental Disabilities Services concluded that "... some states have struggled to maintain a sufficient number of qualified case managers to adequately address the needs of service recipients."<sup>15</sup> Increased funding alone, however, will not solve the problem. Case management systems also face the challenge of reconciling their role as a system gatekeeper with their frequently conflicting responsibility to advocate on behalf of the individuals they serve. Moreover, given the recent growth in self-directed services, new support models that balance choice and system-wide accountability are required to accommodate the needs of individuals and families who elect to manage their own services.

In response to Congressional criticism,<sup>16</sup> the Centers for Medicare and Medicaid Services (CMS) has been

prodding states in recent years to improve the quality of home and community-based services by designing and implementing comprehensive quality management systems. As a result, today states have broader capabilities to monitor service quality, identify deficiencies and institute corrective actions than they have had in the past. Yet, despite these improvements, quality for the most part continues to be measured in terms of input and process standards, rather than the achievement of measurable, person-centered outcomes. A variety of quality of life assessment tools have been developed over the past thirty years and are now widely used to pinpoint needs, develop individual service goals and, increasingly, to allocate resources on a person-by-person basis. However, comparatively few direct, validated measures of service outcome and performance exist today and those which exist do not provide a solid foundation upon which to base future programmatic initiatives and formulate resource allocation strategies. The agonizingly slow rate of progress in developing outcome and performance measurement systems reflects the complexities of the tasks involved (e.g., determining the meaning and measuring the essential components of “a quality life,” given the diversity of needs and aspirations among the target population); but, the absence of federal and state support for a robust research and development program in this area also has been a contributing factor.

Over the past few years, a number of states have significantly improved their I/DD management information systems. But, by and large the resulting systems are designed primarily to support discrete system-wide management functions within the I/DD network (e.g., monitoring incidents; establishing payment rates and administering vendor payment systems; and/or tracking service utilization and unmet (waiting list) demands). With the exception of a few states, these systems operate in parallel with the state’s Medicaid Management Information System (MMIS), rather than functioning as an integrated component of the MMIS. States which have attempted to add specialized I/DD components to their MMISs frequently have encountered federal roadblocks to qualifying for enhanced federal financial participation in the cost of such MMIS improvements.<sup>17</sup> And, despite information system gaps and discontinuities at least as glaring as those facing the acute health care sector, few observers anticipate that a sizable portion of the \$19.2 billion set

aside in the economic stimulus legislation to improve health information systems will be used to upgrade MIS capabilities in the long-term services sector.

Studies of the comparative effectiveness of I/DD services have focused mainly on the cost-effectiveness of community services. There are a large number of studies of the costs and outcomes of deinstitutionalization, most of which reveal “... a consistent pattern across states and over time of better outcomes and lower costs in the community.” Other studies have uncovered “fairly consistent differences in both outcomes and costs” between different types of community residential settings; but, little or no comparative data is currently available on the relationship between expenditures and outcomes within particular types of services.<sup>18</sup> In other words, there are studies which shed light on the most cost-effective service settings, but very little empirical data to guide decisions regarding the most efficacious intervention strategies given the nature of an individual’s support needs. This lack of data reaches across the entire service spectrum, from early intervention services for developmentally delayed infants, to behavioral intervention services for adolescents and adults, to supports for older persons with developmental disabilities. Society desperately needs more effective methods of deploying available resources if the continuing upward spiral in demand for long-term supports is to be effectively addressed. And, as is the case in the acute health sector, the key to improved resource allocation decisions is more and better studies documenting the comparative effectiveness of alternative intervention strategies.

In its recent report to the President and Congress, the Federal Coordinating Council for Comparative Effectiveness Research, a body created as part of the economic stimulus legislation, recommended that individuals with disabilities be designed a “priority population” in conducting such research. The council also identified several potentially fruitful areas of inquiry related to disability and disability services, including studies of the comparative effectiveness of alternative models of community-based care. In order to ensure that such studies are properly designed and the findings promptly disseminated and effectively applied, it will be important that disabilities stakeholders are actively engaged in the conduct of these studies.<sup>19</sup>

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.
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- <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>.
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- <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

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