

Will National Health Reform Help Individuals with Developmental Disabilities?

ABSTRACT: As the Obama Administration and Congress develop legislation to revamp the American health care system, one largely unexplored area is the impact impending changes in national health care policy might have on long-term services and supports for individuals with chronic disabilities. This report, the first in a two part series, explores the potential ramifications of various proposals to restructure the financing and delivery of long-term services from the perspective of people with intellectual and developmental disabilities.

Federal-state Medicaid dollars are the primary source of funding for long-term services and supports to individuals with intellectual and developmental disabilities. According to researchers at the University of Colorado's Coleman Institute for Cognitive Disabilities, over three-quarters (78%) of all public spending on specialized developmental disabilities services in 2006 was derived from federal-state Medicaid payments.¹ Yet, as the nation examines the merits of a variety of proposed reforms in health care policy, little attention has been focused on the impact such legislation may have on future Medicaid funding in general and funding for services to persons with developmental disabilities in particular.

The purpose of this "Policy Insights" report is to analyze the provisions of major health reform proposals and assess their likely impacts on existing arrangements for financing and delivering specialized services to persons with developmental disabilities. More specifically, the report examines alternative strategies for restructuring federal policies governing long-term supports for persons with developmental disabilities, possibly as part of a global health reform agenda. A later report in this series will explore the similarities and differences in underlying strategies for restructuring health care and long-term services in the United States.

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 second 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. 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.

Background

The promise to reform the American health care system was a centerpiece of President Barack Obama's successful 2008 election campaign. Since the election, Mr. Obama has assigned top priority to stimulating a rapidly deteriorating national economy. But, all of the signals thus far suggest that the President is prepared to forge ahead with efforts to pass health reform legislation this year. Indeed, proponents suggest that the passage of such legislation is critical to sustaining any economic recovery over the long haul. They point to estimates suggesting that as much as 20 to 30 percent of existing health expenditures, or at least \$500 billion a year, are directed toward useless or potentially harmful care. Even modest reforms in the health care delivery system, they contend, could save billions of dollars annually. An analysis of a comprehensive health system overhaul bill introduced in 2007 by a bipartisan group of senators, for example, estimates savings of \$1.4 trillion dollars over 10 years, assuming coverage for all Americans combined with assertive steps to improve system-wide efficiency, prevent fraud and abuse and eliminate unnecessary care.²

During his campaign for the presidency, Mr. Obama promised on numerous occasions to enact health reform legislation before the end of his first term. Since the election, he has reiterated this pledge and signaled repeatedly the importance he attaches to reforming the nation's health care system. The withdrawal of the nomination of former Senate Majority Leader Tom Daschle as Secretary of Health and Human Services and the selection of a replacement (former Kansas Governor, Kathleen Sebelius) delayed temporarily the rollout of the new Administration's health agenda. President Obama, however, has backed up his promise to reform the health care system by including approximately \$150 billion of new health care funds in the economic stimulus measure enacted by Congress in February and calling for the establishment of a \$634 billion trust fund over the next 10 years to cover the front-end costs of expanding health services to all Americans (see additional discussion below). These initiatives are characterized by Administration officials as a down payment on the President's promise to reform the American health care system.

Despite many unresolved issues, Congress at the moment appears poised to enact sweeping changes in national health care policy before the end of 2009. Both House and Senate leaders have indicated they plan to bring a health reform bill to a floor vote before the annual August recess and have a final, compromise measure on the President's desk by the fall. In contrast to the mid-1990s when the Clinton health reform plan was under consideration, key conservatives from both parties, including right-leaning Democrats and moderate Republicans (especially in the Senate), have been participating in a bipartisan effort to forge a measure that can draw support from both sides of the aisle. The current sense of optimism could dissipate once both chambers begin to hammer out the details of the legislation and, critically, decide how to pay for its huge, additional costs. Reaching agreement on the appropriate mix of reform strategies and financing methods unquestionably will be challenging. There are simply too many competing interests with a great deal to gain or lose for legislation of this magnitude to sail through Congress. Balancing these interests within a modernized, sustainably financed health

care system will require an act of political jujitsu rarely achieved within the annals of American history. As a result, the timing and eventual contents of health reform legislation remain unsettled at the present time. Among many unanswered questions is: how will long-term supports for persons with developmental and other disabilities be influenced by impending changes in federal health care laws?

The Fundamentals of a Comprehensive Health Reform Strategy

During the 2008 political campaign, Candidate Obama sought to steer a course between “government run health care with higher taxes and letting ... [private] insurance companies operate without rules.”³ The reform plan he outlined during the campaign seeks to strengthen employer-based health plans, hold insurance companies accountable and guarantee Americans the right to choose their own doctors and health plans. By building on the existing health care delivery system, Obama’s stated aim is to provide affordable, accessible health care for all Americans.

Learning from failed reform efforts of the past (especially the demise of the Clinton health plan in the mid-1990s), the President has decided to allow Congress to take the lead in developing health care reform legislation. Not surprisingly, given the fact that Democrats hold a clear majority in both chambers of Congress, the plan which is beginning to emerge adheres to the broad outlines of the approach described by Candidate Obama and his running mate Senator Joe Biden. The President and key Administration officials have been urging Congress to act swiftly while making it clear that they are prepared to intervene if the process bogs down or becomes sidetracked. We don’t know the specifics of the emerging plan at this point. But, we can draw reasonable inferences by examining the proposals advanced by the President’s Capitol Hill allies.

During the 110th Congress, a bipartisan group of senators, led by Senator Ron Wyden (D-OR) and Senator Bob Bennett (R-UT), introduced a measure called the “Healthy Americans Act” (S. 334),⁴ which shares some of the key aims of the Obama plan. More recently, several key Congressional leaders, including Senator Edward Kennedy (D-MA), chairman of the Senate Health, Education, Labor and Pension Reform Committee (HELP), and Senator Max Baucus (D-MT), chairman of the Senate Finance Committee, have been developing their own health reform measures with the intention of introducing separate Senate bills within the next month or so. As the work of these two committees – as well as the parallel work of the responsible House committees – advance, the principal components of a health reform plan are becoming evident. In order to avoid potentially disruptive jurisdictional battles, the leadership of the House and Senate are coordinating the work of the key committees with legislative jurisdiction in both chambers. For example, at the request of Senate Majority Leader Harry Ried (D-NV), the chairmen and ranking minority members of the Finance and HELP committees have agreed to synchronize their efforts – and to maintain close liaison with the Obama Administration – as they formulate legislation to restructure the American health care system. Similar procedures are in place in the House of Representatives to

coordinate the work of three, responsible House committees (i.e., Energy and Commerce; Ways and Means; and Education and Labor).

While the specifics of the forthcoming health reform measures remain sketchy, the basic outline is clear. The central aim will be to modify rather than replace the nation's existing health care delivery system. By strengthening and reorienting the existing system, the aim will be to ensure that all (or at least most) Americans have access to health care. The general goals will be to:

- Guarantee universal access to health care by offering a range of affordable public and private health insurance plans, subsidizing insurance premiums for low-to-moderate income individuals and families, and, possibly, requiring all adults to be insured.
- Promote cost-effective and affordable health care by:
 - (a) strengthening the role of primary care and chronic care management within the health care system;
 - (b) realigning payment incentives to promote wellness and quality outcomes;
 - (c) fostering collaboration and accountability among providers of health care;
 - and (d) improving the health care delivery infrastructure.
- Institute financial reforms aimed at improving system-wide efficiency by:
 - (a) intensifying efforts to root out fraud, waste and abuse;
 - (b) improving the transparency of health transactions;
 - (c) reforming medical malpractice policies;
 - (d) modernizing health information technology;
 - (e) establishing tax incentives which promote health coverage and healthy lifestyles;
 - (f) emphasizing prevention and wellness initiatives; and
 - (g) restructuring the role of private health insurance plans under Medicare.

Essential Elements of a Health Reform Strategy

Universal Access to Health Care

- A range of public & private health plans;
- Low-income subsidies;
- Individual coverage mandate

Improved Cost Effectiveness

- Strengthen primary/chronic care
- Realign payment incentives to promote wellness/prevention
- Promote accountability & provider collaboration
- Improve care infrastructure

More Efficient System-wide Financing

- Root out fraud, waste & abuse
- Improve transparency
- Reform malpractice coverage
- Modernize information technology
- Use tax incentives to promote coverage & healthy lifestyles
- Emphasize prevention & wellness
- Restructure private health coverage under Medicare

All of the major health reform plans advanced to date seek to accomplish many of the above goals but by employing somewhat different strategies. These differences are important and, no doubt, will be the source of heated debate as health reform measures wend their way through the legislative process. That is as it should be, since the details are critical if effective and sustainable changes in the American health care system are to be instituted. But, for purposes of the present discussion, let's sidestep the details of the forthcoming legislation and focus instead on possible strategies for reforming long-term services and supports as part of a global health reform measure. Before doing so, however, let us briefly examine the implications of the health care provisions of the recently enacted economic stimulus legislation.

Health Care Reform and Economic Stimulus

In signing into law the "American Recovery and Reinvestment Act" (ARRA; H.R. 1; P.L. 111-5) on February 17th, President Obama remarked that his Administration has "...

done more in 30 days to advance the cause of health reform than the country has done in an entire decade."⁵ There may be a bit of political hyperbole in the President's statement, but unquestionably the newly enacted economic stimulus legislation includes funds to support far-reaching steps to stabilize access to health care services and modernize the infrastructure of the health industry over the next few years.

The ARRA is one of the most sweeping economic relief measures ever enacted by Congress. It commits the federal government to spending a total of \$787 billion over the next few years to jump start the American economy. The stimulus legislation is one prong of the Obama Administration's three-part strategy for addressing what economists are calling the worst recession since the Great Depression of the 1930s. The other key elements of the Administration's strategy include plans to stabilize and restore confidence in the nation's financial markets and to stem the steep rise in housing foreclosures.

Of the total funds included in the economic stimulus measure, about \$144 billion, or 18 percent, is targeted to helping state and

Health Care Provisions: American Recovery and Reinvestment Act

- Comparative Effectiveness Research: \$1.1 B
- Health insurance coverage of unemployed workers: \$24.7 billion
- Construction/renovation of DoD & VA health care facilities: \$1.4 B
- Health information technology: \$19.2 B
- Community health centers construction, equipment, info technology, services and related activities: \$2.5 B
- Payments to Medicare teaching hospitals, hospices & LTC hospitals: \$338 M
- Enhancements in Medicaid matching rates: \$87 B
- Expanded NIH research & construction/renovation of NIH building: \$10.0 B
- Expanding prevention & wellness grants; increased immunizations: \$1.0 B
- Improved security of health information: \$50 M

local governments weather the effects of precipitous revenue declines that are a direct by-product of the current recession. Slightly over 60 percent of this total state-local aid, or \$87 billion, is to be channeled to the states through enhanced federal financial participation in the cost of Medicaid services. The remainder (\$57 billion) will be used to underwrite the cost of transportation and other public infrastructure improvements and to boost federal aid for a variety of health, education and social programs. The latter category includes a \$12.2 billion increase for special education and early intervention services, plus a \$540 million increase for vocational rehabilitation services.

The enhanced federal share of Medicaid costs will help states to: (a) address the expected influx of new enrollees as the number of unemployed workers grows; and (b) avoid deep cuts in existing Medicaid-funded services which otherwise would be necessary to balance state budgets. Under the terms of the ARRA, states that were anticipating a decrease in their federal Medicaid financial participation (FMAP) rate will be held harmless at their old rate through the first quarter of FY 2011. Each state moreover is eligible to receive an across-the-board FMAP increase of 6.2 percent over a 27-month period (beginning in October 2008 and continuing through December 2011). In addition, states with elevated unemployment rates will receive an additional boost in their FMAP rates. State experiencing a 1.5 percent to 2.5 percent increase in unemployment, compared to a base period, will receive an additional 5.5 percent FMAP increase; states experiencing higher unemployment rates will receive proportionally larger FMAP increases – i.e., an 8.5 percent increase for states with unemployment rate increases of between 2.5 percent and 3.5 percent; and an 11.5 percent add-on for states with unemployment rate increases of over 3.5 percent. The net effect is that FMAP rates in all states will rise by 7.5 to 14.0 percentage points over the next two fiscal years, with the possibility of later upward adjustments (but no decreases) should unemployment rates rise even higher.

Besides the enhanced FMAP rates, the ARRA also includes higher federal funding levels for a variety of existing programs as well as new spending initiatives tied to the Administration's plans to reform the American health care system. Overall, the legislation includes an estimated \$150 billion in new health care funding (see accompanying textbox).⁶ The funding most directly related to the President's health care reform efforts are: (a) the \$19.2 billion set aside to promote the use of electronic health records and otherwise stimulate improvements in information technology; and (b) the \$1.1 billion earmarked for comparative effectiveness studies aimed at improving the efficiency and effectiveness of health care expenditures system-wide.

Entitlement Reforms

In addition to reforming the nation's health care system – while at the same time promoting the use of clean, sustainable energy sources and building a 21st Century education system – President Obama has promised to cut the spiraling federal deficit in half by the end of his first term.⁷ The White House released the broad outline of the President's revised 10-year budget plan to accomplish these objectives on February

26.⁸ A more detailed budget for FY 2010 and beyond was sent to Congress on May 7. The current plan relies on four major strategies to reduce deficit spending. These strategies are aimed at restoring the vitality of national economy, allowing the Bush tax cuts for high-income families and corporations to expire at the end of 2010, winding down the United States' involvement in the Iraq war, and improving the efficiency of programs government-wide.

One of the highlights of the President's new budget plan is a proposal to create a \$634 billion health reserve fund over the next 10 years to cover the cost of expanding health insurance coverage to millions of uninsured Americans. Half the funds for this new reserve account are to be derived from new, unspecified revenue sources, while the other half will come from savings achieved through enhanced efficiency, accountability and cost sharing. The assumption is that most of the latter dollars will be generated by streamlining the Medicare and Medicaid programs.

During a late February press briefing on the new Obama budget, Office of Management and Budget (OMB) director, Peter Orszag, called modernizing the health care system "the driving force in our [plan to close the] long-term fiscal gap." He added that reforming the health system is "... the single most important thing we could do ..." to eliminate deficit spending.⁹ Among the strategies for improving the efficiency of the health care system highlighted by Orszag were improvements in health information technology and the elimination of wasteful spending by focusing on health interventions of proven effectiveness. Extensive evidence, he said, suggests that as much as \$700 billion is spent each year on health tests, procedures and medications that are unnecessary. These expenditures, Orszag added, drive up health care costs to the government and individuals "without making anyone healthier."

Restructuring the government's two major health care programs – Medicare and Medicaid – will form the centerpiece of the Obama Administration's efforts to contain the growth in health care spending. Together these two programs account for over \$700 billion of federal expenditures per year; when the states' share of Medicaid outlays is included, the two programs are the source of nearly a trillion dollars of health outlays annually. Medicare and Medicaid spending, consequently, is the Administration's principal leverage point as it attempts to improve the efficiency of the American health care system.

Forthcoming efforts to reform Medicare and Medicaid policies almost certainly will spill over to long-term services, which presently represents roughly one-third of all Medicaid outlays. Expenditures on behalf of persons with developmental and other disabilities make up a disproportionate share of total Medicaid services spending. In 2005, non-elderly persons with disabilities constituted 14 percent of all beneficiaries of Medicaid services but accounted for 42 percent of all program outlays.¹⁰ Under the circumstances, it would be foolish to assume that legislation intended to streamline Medicare and Medicaid spending will have little or no impact on future funding of long-term services and supports to individuals with intellectual and developmental disabilities.

Reforming Long-Term Care Policies

Thus far, discussions of health care reform have focused almost exclusively on the adoption of new strategies for financing and delivering preventive, primary and acute care services. Potential changes in federal long-term care policies have been largely ignored or pushed to a back burner.

Many health reformers acknowledge the need to restructure long-term services; but beyond articulating broad, aspirational goals, they offer few fresh policy initiatives. For example, a white paper on health reform issued by Senate Finance Committee Chairman Max Baucus last December points out that the existing long-term care system "... is expensive, inefficient and

Long-term care has been largely ignored thus far in the health reform debate

does not encourage the delivery of high-quality care."¹¹ But, its prescription for addressing these problems adds up to little more than a continuation of the policies the federal government and the states have been pursuing over the last two decades: a stronger emphasis on home and community-based versus institutional services; improved coordination of Medicare and Medicaid services to dually-eligible beneficiaries; earlier access to supports in order to prevent the progression of debilitating conditions; more and better supports for family caregivers, including assistance in locating appropriate services and supports for their loved ones; piloting new models of institutional care, such as the Green House model; improved care coordination and disease management services; and making private long-term insurance policies more affordable and accessible. This is an agenda calling for "more of the same" rather than substantive reforms.

The long-term care provisions of the Healthy Americans Act also are narrowly focused. The bill, as introduced, would direct the Secretary of Health and Human Services to approve statutory waivers requested by states desirous of pursuing broad-scale long-term care reforms similar to Vermont's "Choice for Care" 1115 waiver program, which is aimed at expanding home and community-based support options for frail elders and adults with qualifying physical disabilities (Sec. 311, S. 334). The bill also would establish federal standards governing private long-term care insurance policies in an attempt to make such coverage simpler and more affordable. Otherwise, the legislation focuses entirely on restructuring the financing and delivery of preventive and acute care services.

In opening a recent Senate Finance Committee hearing on revamping federal long-term care policy in the context of health reform legislation, Senator John D. Rockefeller (D-WV) pointed out that it has been almost 20 years since Congress substantively (and, as it turned out, unsuccessfully) addressed the topic of long-term care. In the meantime, the gaps and discontinuities in long-term services have widened while expenditures from all sources have more than quadrupled (growing from \$53 in 1988 to \$233.4 billion in 2007). "Just as there are opportunities to align provider payments with

better patient health outcomes for acute care,” Senator Rockefeller said, “there are also significant opportunities to improve the quality of long-term care... As we embark on comprehensive health reform,” he concluded, “it is imperative that long-term care be part of the solution.”¹² Yet, as the principal elements of a broad health reform strategy take shape, the nature and extent of accompanying reforms in long-term services policies remains largely off the Congressional radar screen.

Existing Bills

During the 110th Congress, various bills designed to improve the accessibility, quality and cost-effectiveness of long-term services were introduced in the House and the Senate.¹³ Among the most prominent measures were the:

- Independence at Home Act (S.3613 (Wyden); H.R. 7114 (Markey)). This bill would establish a three-year Medicare demonstration project using a patient-centered health care delivery model to ensure program beneficiaries with multiple chronic conditions remain independent as long as possible. Each Independence at Home (IAH) patient would receive a comprehensive needs assessment at least annually and access to treatment services through an IAH organization.
- Empowered at Home Act (S. 3347 (Kerry); H.R. 7212 (Pallone)). This bill would:
 - (a) replace the current income limit applicable to the receipt of Medicaid home and community-based state plan services under Sec. 1915(i) of the Social Security Act (i.e., 150% of poverty) with a new, higher standard (300% of the SSI payment standard);
 - (b) permit the coverage of “other” types of services (i.e., besides those mentioned in existing law) if approved by the Secretary;
 - (c) allow states to cover services to multiple target groups, in much the same way as they define distinctive population groups to receive targeted case management services under existing law;
 - (d) remove the cap on the number of persons who receive Sec. 1915(i) HCB services;
 - (e) apply current spousal impoverishment standards applicable to new nursing facility recipients to beneficiaries of home and community-based care;
 - (f) provide tax relief to family caregivers who purchase meaningful private long-term care insurance; and
 - (g) authorize grants to help states increase the supply of high quality care workers, promote healthy behaviors and make community-based services more consumer-centered.
- Community Choice Act (S. 799 (Harkin); H.R. 1621 (Davis)). This measure would require states to offer community-based attendant services and supports (CBASS) under their Medicaid plans to all beneficiaries meeting nursing facility or ICF/MR level of care criteria. Consumers electing CBASS services could choose among various service delivery models, including vouchers, direct cash payments, fiscal agents and service providers. But, services would have to be provided in the most integrated setting appropriate to the individual’s needs.

States would receive a temporary enhancement in their federal Medicaid share in order to help cover the costs of this new mandatory coverage.

- Community Living Assistance Services and Supports (CLASS) Act (S. 1758 (Kennedy); H.R. 7212 (Dingell)). This bill would create a voluntary, national, premium-based disability insurance program outside of Medicaid and Medicare. Workers would be automatically enrolled, but would be allowed to decline participation. Participants would be required to pay monthly premiums and, should they become disabled, the program would provide cash benefits to help them purchase non-medical services and supports. Among the key operating features of the program would be: (a) all employees would be automatically enrolled but permitted to waive enrollment if they chose not to participate; (b) automatic payroll deductions (of approximately \$30 a month) would be authorized to cover the cost of the monthly premiums; and (c) a two-tiered system of benefits would be created, depending on the severity of the insured person's disability, to purchase services and supports that the beneficiary needs to maintain independence. To qualify for benefits, a Tier 1 beneficiary would have to have paid premiums for at least 5 years and be unable to perform at least two activities of daily living (a comparable test would apply to persons with cognitive or psychiatric disabilities). The same years of coverage requirement would apply to Tier 2 beneficiaries, except to qualify beneficiaries would have to be unable to perform three or more activities of daily living (or an equivalent test of severity for persons with cognitive or psychiatric disabilities). Both Medicaid and non-Medicaid beneficiaries would be eligible to participate.
- Direct Support Professionals Fairness and Security Act (H.R. 1279 (Capp)). This bill would amend Medicaid law to provide enhanced federal financial participation (FFP) in the cost of increasing the wages of direct support professionals (DSPs) who furnish services and supports to persons with disabilities. To qualify for enhanced FFP, a state would be required to submit a 5-year plan spelling out the steps it will take to increase the wages of DSPs and offering assurances that such wage increases would be sustained following the end of the plan period. The enhanced federal Medicaid assistance percentage (FMAP) rate would apply to wages paid to direct support professionals furnishing services under the ICF/MR state plan option, the HCB waiver authority, the Section 1115 waiver authority and various other Medicaid state plan options (e.g., personal care; rehabilitative services; and home health services) to persons with disabilities.

Recent Proposals

In recent weeks, the Senate Finance Committee has held a series of closed door meetings to discuss optional approaches to restructuring the American health care system. In conjunction with this review, committee chair Max Baucus and ranking minority member Charles Grassley (R-IA) have released a series of three issue papers outlining alternative ways of expanding access to health care, improving eligibility and

coverage, and financing a revamped health care delivery system.¹⁴ Senators Baucus and Grassley made clear in an accompanying press release that they do not necessarily endorse the proposals contained in these papers, but rather were putting them forward in an attempt to focus the discussion and build a bipartisan consensus within the committee around the specific mix of statutory changes that should be part of a comprehensive health reform measure. The aim is to introduce a bill sometime in June that will be marked up in the committee. The Finance Committee's bill then will be merged with a companion measure being developed by the Senate Health, Education, Labor and Pensions Committee and the consolidated bill will be brought to the floor for a vote.

The results of the Finance Committee's deliberations will not be known for several weeks; and, given the division of legislative jurisdiction within the two chambers, the contents of the final, amalgamated Senate and House versions of a health reform bill won't be available until mid-to-late July. No doubt, there will be many twists and turns along the way. Nonetheless, the options currently under consideration within the Senate Finance Committee offer a window into the key reforms under consideration as well as the critical choices which must be made. Because this report focuses on long-term services policies and, in particular, their ramifications for persons with intellectual and developmental disabilities, the following analysis is based primarily on the policy options outlined in the Finance Committee's paper on eligibility and coverage policy. Since the committee's option papers do not lay out the rationale for adopting any of the proposed statutory changes, our analysis also draw upon information contained in an earlier compendium of health reform policy options released late last year by the Congressional Budget Office.¹⁵

The following is a brief synthesis of the major long-term services reforms currently under consideration within the Senate Finance Committee:

- Allow states to offer under a Section 1915(i) state plan amendment home and community-based services (HCBS) other than those listed in Section 1915(c) of the Act. The proposal is identical to a provision of S. 3347/H.R. 7212 (see discussion above). The aim is to remove an impediment that has discouraged states from adopting the Section 1915(i) state plan coverage.
- Permit eligible individuals to be simultaneously enrolled in two or more Medicaid waiver programs. The purpose of this amendment would be to afford states the flexibility to "mix and match" community supports for eligible persons with long-term service needs by permitting an individual to be simultaneously enrolled in two or more waiver programs under Section 1915 of the Act.
- Eliminate the present link between eligibility for home and community-based waiver services under Section 1915(c) and the institutional needs test and require states to substitute less stringent eligibility criteria. This proposal is similar to a provision of S. 3347/H.R. 7212, except it would apply to Section

1915(c) waiver programs instead of the Section 1915(i) Medicaid state plan coverage option.

- Eliminate the provision of Section 1915(i) prohibiting states from offering HCB state plan services to persons with income over 150 percent of the poverty level and allow states to set a higher income eligibility standard as long as the level established is no higher than 300 percent of the maximum federal SSI payment standard. Again this proposal is identical to a provision of H.R. 3347/H.R. 7212.
- Consider placing federal restrictions on a state's authority to cap enrollment in Section 1915(c) waiver programs as well as participation in Section 1915(i) state plan services. The Finance Committee's options paper identifies two alternative approaches to imposing such restrictions and solicits suggestions from committee members on other possible ways of ensuring that eligible beneficiaries gain access to needed HCB services. The first approach would mandate that participating states increase enrollment levels under the HCBS waiver programs they operate. The methodology to be used in calculating such mandatory enrollment increases is not elucidated in the paper. Second, states would be prohibited from wait-listing persons eligible to receive HCBS, thus, presumably, turning waiver services into an open-ended entitlement for eligible members of the target population. In its December 2008 report, CBO estimated that it would cost the federal government \$20 billion over 5 years and \$90 billion over 10 years if HCBS services were to become a mandatory Medicaid state plan coverage. The cost impact of this proposal, however, might be less – possibly considerably less – should states decide to discontinue a significant number of HCBS waiver programs due to a sharp increase state matching outlays.
- Authorize a differentially higher federal matching rate for HCBS services compared to institutional services. The proposal as outlined in the Finance Committee's option paper would increase the federal matching ratio for home and community-based services by one (1) percentage point above the otherwise applicable rate. This proposal is similar in some respects to a key provision of the Community Choice Act, except the differential federal matching ratio would be much lower and, presumably, permanent rather than temporary in nature. In its December 2008 report, CBO estimated that a five (5) percentage point increase in the federal share of HCBS costs and a corresponding decrease in the federal share of institutional costs would result in an \$8 billion increase in federal outlays over 5 years and a \$13 billion increase over 10 years if the reduction in the federal institutional matching ratio were to be delayed until January 2012 to allow states sufficient time to ramp up HCB capacity.
- Establish a new Medicaid demonstration authority aimed at allowing states to test out alternative approaches to coordinating health care for dual eligibles (i.e., persons who are eligible to receive both Medicare and Medicaid benefits). Under this new authority, the Secretary would be empowered to approve statutory

waivers that allow the requesting state to initiate such coordinated care arrangements over a 5- year period.

- Allow states to count Medicare savings resulting from care coordination for dual eligibles in calculating the cost-effectiveness of Section 1915(b) waiver programs. Because Medicare is the first payer and covers most acute health care costs for dual eligible, states have complained that the federal government often realizes most of the savings associated with coordinated care and, consequently, it is hard for states to demonstrate the cost effectiveness of Section 1915(b) managed care waivers without including Medicare savings. The proposed statutory amendment would correct this problem.
- Establish a high level Office of Coordination for Dually Eligible Beneficiaries within the Centers for Medicare and Medicaid Services. This office would be the lead unit within CMS in synchronizing Medicare and Medicaid policies so states would be able to take greater advantage of opportunities to improve the cost-effectiveness and overall efficacy of health and long-term services to dual eligibles.
- Reduce or phase-out the 24-month waiting period before a person under 65 years of age who is found eligible for Social Security or Railroad Retirement benefits on the basis of disability may qualify for Medicare Part A benefits. The Finance Committee's option paper outlines four alternative approaches to altering the required waiting period. Under Approach #1, the waiting period would be reduced to 12 months, beginning in October 2009. Under Approach #2, the waiting period would be reduced by one month every quarter beginning in October 2009 until it reaches zero in July 2015. Under Approach #3, the waiting period would be phased out over 18-months as new beneficiaries join the benefit rolls after October 2009, with the first group (those enrolled between October 2009 and March 2010) waiting 18 months and those enrolled after April 2011 having no waiting period. Approach #4 would retain the current 24-month waiting period for all persons with access to qualifying private health insurance coverage which meets or exceeds specified standards. The waiting period for all other beneficiaries would be phased out according to one of the schedules discussed above. As with many of the other proposed statutory changes, costs will be factored into the committee's eventual decision. In a December 2008 report, CBO estimated the net costs of phasing out the 24-month waiting period over a 5-year period at \$11.6 billion in 2013 (after federal Medicaid savings are taken into account).¹⁶ An alternative estimate in a paper recently released by the Commonwealth Fund sets the net cost of eliminating the waiting period at a somewhat lower level without retroactive eligibility (\$7.4 billion) and a somewhat higher level (\$12.0 billion) with full retroactive benefits.¹⁷

The Finance Committee's options paper includes a variety of other proposals to expand Medicaid eligibility and coverage as part of a broader effort to make health insurance available to all Americans. Depending on the alternatives the committee adopts, state

Medicaid programs could undergo extensive changes, especially in states that currently restrict eligibility and benefits to statutory minimums. However, because most persons with intellectual and developmental disabilities qualify for Medicaid benefits on the basis of their SSI eligibility, the proposed statutory modifications would have only an indirect impact on the receipt of long-term services by I/DD beneficiaries. The options paper also contains other provisions aimed at improving access to Medicaid-funded long-term services and supports. For the most part, these proposals are designed to expand access to home and community services among frail elders and other adults with physical disabilities. Among these proposals are: (a) the extension of Medicaid spousal impoverishment rules to HCB services; and (b) authority for recipients of HCB services to retain higher asset levels without losing their Medicaid eligibility. Finally, the paper sketches out a series of proposals to improve long-term services grant programs, including the proposed extension of the Money-Follows-the-Person demonstration program for an additional 5 years (through fiscal year 2016).

Impact of Proposed Reforms on I/DD Long-Term Support Systems

It is unclear at this point which, if any, of the proposals discussed in the preceding sections of this bulletin will find their way into Congressional health reform legislation. It is worth noting, however, that the Obama disability agenda¹⁸ voices support for legislation along the lines of the CLASS Act and the Community Choice Act (as described above). The White House has not yet indicated, however, whether the President is prepared to insist that such legislative proposals be included in the forthcoming health care reform bills. The President's disability agenda also endorses increased funding for autism research, treatment, screening, public awareness and support services. The types of statutory and administrative initiatives the Obama Administration is prepared to pursue in this area (other than seeking additional funding for existing government programs¹⁹), however, has not yet been fleshed out; and, again, we don't know whether the Administration's plans to expand federal autism aid will be pursued separately or as part of the President's health reform initiative.

Despite the current uncertainties, it seems reasonable to assume that the changes in federal long-term services policies which ultimately are included in forthcoming health reform measures will be based largely on the mix of strategies outlined above. Therefore, let us next examine these strategies to determine how they would impact on the financing and delivery of specialized services and supports for persons with developmental disabilities.

Correct defects in the existing Medicaid HCBS state plan coverage option. As proponents of the "Empowerment at Home Act" point out, there are serious defects in the existing statutory authority governing the optional Medicaid state plan coverage of home and community-based services. Although states have been permitted to add this coverage to their Medicaid plans since January 1, 2007, few states have elected to do so – and all of these states have chosen to target services to narrowly defined groups of

recipients who either can't participate, or are difficult to cover, through HCBS waiver programs.

Unquestionably, states would be more inclined to elect this coverage option if the previously-mentioned impediments were removed from existing law. A state plan coverage would offer states a more secure platform for financing home and community-based services moving forward. It is far less certain, however, that expanded use of the state plan option, by itself, would lead to a sizeable increase in the number of enrollees in HCB services – at least in the near term. Faced with declining revenues and increasing demands for social and health services, the current priority in most states is to keep social safety net programs intact in the face of declining revenues. The temporary increase in FMAP rates and other forms of state-local aid authorized under the economic stimulus legislation will help some states to avoid truly devastating spending cuts. But, given the ravages of the recession, most states will have to postpone expansions in HCB services until an economic recovery is well underway.

Offering home and community-based services as an open-ended entitlement. The provision of the “Empowerment at Home Act” tying the removal of statutory impediments in Section 1915(i) to treating such services as an open-ended entitlement would be a definite “deal breaker” for state governments. The same can be said about the option in the Finance Committee’s paper calling for a requirement that states operate Section 1915(c) waiver programs without waiting lists. Congress added these authorities to Medicaid law in order to give states a reliable, ongoing means of financing home and community-based (HCB) services, thus leveling the playing field between HCB services and institutional services. In doing so, federal lawmakers allowed states to limit the number of recipients of Section 1915(c) and 1915(i) services in any given year. One central lesson that can be drawn from the nation’s experience with the HCBS waiver authority over the past 25+ year is that states will expand home and community-based services but only if they are able to keep the rate of expansion within the limits imposed by the matching resources available to them. State expenditures generally may not exceed available revenues during any given fiscal year and, consequently, state policymakers are not in a position to assume new, open-ended financial commitments. Rather than expanding access to HCB services, the inevitable result of converting Section 1915(c) and/or 1915(i) services into an open-ended entitlement – especially in the current, troubled fiscal environment – is that states would be forced to scale back the number of Section 1915(c) waiver programs they operate or, in the case of the Section 1915(i), avoid adopting this coverage option for any target group.

From an I/DD perspective, however, should Congress choose to require states to expand HCB services furnished under the Section 1915(c) or the Section 1915(i) authority, the approach sketched out in the Finance

The elimination of spending and utilization caps under the Medicaid HCBS state plan option would be a deal breaker for the states

Committee's paper – i.e., one that applies to all HCB services, whether offered through a state HCBS plan coverage, Secretarial waivers or a combination of both – is preferable to a mandate applied to personal/attendant care services only. Under the most recent iteration of this Community Choice Act (CCA), the target population includes all persons with disabilities who are at-risk of placement in long-term care institutions (i.e., nursing facilities, institutions for mental diseases (IMD) and ICFs/MR). Clearly, therefore, some individuals with intellectual and developmental disabilities would benefit from expanded access to attendant services and supports. But, the CCA would leave many needs among persons with more, complex disabilities largely unaddressed. Ample evidence of this fact can be found in the home and community-based waiver programs which states currently operate for persons with developmental disabilities. While many states offer personal assistance/attendant care services through their MR/DD waiver programs, they also cover a wide range of other services because they have learned over the years that a broad menu of community services and supports is required if sustainable, high-quality alternatives to institutional care are to be created for the entire range of persons with intellectual and developmental disabilities.

Due to the lifelong impact of a developmental disability, a much larger portion of participants in MR/DD waiver programs need a supervised living arrangement than is the case in waiver programs serving frail elders and persons with physical disabilities. This is the principal reason why in 2004 the average per participant cost of MR/DD waiver services was approximately six times higher than the average per participant cost of elderly waiver services and four times higher than elderly/disabled waiver services.²⁰ Most MR/DD stakeholders welcome the emphasis in S. 799/H.R. 1621 on affording persons with disabilities expanded opportunities to self-direct their services and supports and recognize that within the I/DD sector the emphasis on creating smaller, more personalized and integrated community living settings needs to continue. Improved access to community attendant services and supports, however, will not change the current situation appreciably. To buttress the point, let's examine the likely impacts on four of the major challenges currently facing state/local DD service delivery systems:

- Long waiting lists for out-of-home living arrangements. The primary – indeed virtually the only – reason I/DD waiting lists exist today is the inability of most states to keep pace with the growing demand for sheltered living settings in the community that are capable of meeting the varied support needs of young to middle-aged to older adults with substantial developmental disabilities. For persons with mild intellectual disabilities and no significant secondary conditions, attendant services can be a viable alternative; but, the bulk of wait-listed adults need more than intermittent in-home supports in order to succeed in the community. For such individuals a more structured, supervised living environment is required.
- The pressing need for employment supports among working-age adults with developmental disabilities. Expanded access to attendant care services will not

address the acute shortage of employment supports, especially among adolescents and young adults with developmental disabilities. Individuals with intellectual and developmental disabilities often require prolonged on-the-job supports in order to engage in remunerative employment. These types of supports typically are not available through state vocational rehabilitation programs. Yet, the cost-effectiveness of emphasizing employment outcomes has been demonstrated in numerous studies, both in terms of the recipient's enhanced economic self-sufficiency as well as the reduced costs of other long-term supports.

- The rapid increase in the number of adolescents and young adults with autism spectrum disorders who need intensive behavioral intervention services. These young people make up a sizeable portion of new applicants for state/local I/DD services across the country. They need extensive (in-home) therapies to supplement the special education services they receive during their school years and frequently ongoing community services and supports as adults if they are to avoid institutionalization and become productive members of society. The availability of attendant services will do little to address the needs of this burgeoning, un-served and under-served segment of the I/DD population.
- Inadequate access to behavioral services and supports. Anti-social and dangerous behavior is by far the leading reason why children and adults with developmental disabilities are admitted to institutions – and it also is the most significant barrier to returning current institutional residents to the community. Serious behavioral disorders are two or three times as prevalent among the I/DD population as they are among the general public;²¹ and, while many states and localities have taken steps in recent years to improve access to community-based behavioral services (including crisis intervention services), the absence of such services remains one of the principal impediments to expanding and improving the quality of the community long-term supports available to persons with intellectual and developmental disabilities. Here again, the needs of persons with co-occurring developmental and behavioral disabilities cannot be adequately addressed through attendant care services alone.

Proponents of the Community Choice Act are right in arguing that, as long as nursing facility services for adults is treated as a mandatory coverage under Medicaid, community attendant services should be assigned the same status. They also are right in insisting that service recipients have the option of choosing to remain in the community while receiving the services and support they need to live full, productive lives. But, in the case of persons with intellectual and developmental disabilities, it is important that any statutory mandate encompass a wide range of home and community-based supports – not just attendant services and supports – if such services are to function as a true alternative to ICF/MR services. That is the key lesson which emerges from the states' 25+ years of experience in operating HCBS waiver programs for this target population.

Establish a higher federal matching ratio for HCBS than for institutional services.

Both the Direct Support Professionals Fairness and Security Act and the Community Choice Act rely on differentially higher matching ratios to spur states to improve particular aspects of their Medicaid programs (i.e., expand access to community-based attendant services in the case of the CCA and increase wages and benefits to direct support professionals in the case of the DSPFSA). Historically, differential matching ratios have been used by Congress to encourage states to act on health issues deemed to be of national priority. For example, when Congress decided in 1997 to extend government-subsidized health insurance to children in families with incomes somewhat above the Medicaid financial eligibility threshold, it established an enhanced federal matching ratio for State Children's Health Insurance Program (SCHIP) benefits. Due to the lower state share of enrollment costs (whether eligible children are enrolled in the state's Medicaid program or in private health insurance plans), states were able to substantially reduce the number of uninsured children.

Are differential matching ratios a viable strategy for leveraging desired changes in the long-term services arena and, if so, how wide does the gap between the federal HCBS matching rate and the institutional matching rate have to be in order to induce states to accelerate the shift toward home and community-based services? Experience with the Money-Follows-the-Person demonstration program to date suggests that the gap must be reasonably wide. Certainly, it seems doubtful that a one percentage point increase in the federal HCBS matching ratio, as suggested in the Senate Finance Committee's option paper, would have a significant impact on state decision-making in this area, even if the higher matching ratio were in effect permanently. More importantly, the enhanced federal financial participation must be sustained over a multi-year period before states are likely to commit to major system change initiatives. Especially during the present troubled fiscal times, states are wary of the out-year costs they will have to absorb and, consequently, can be expected to proceed cautiously in undertaking new initiatives with costly out-year costs.

In discussing the merits of setting a higher federal matching ratio for HCB services, it is important to acknowledge that, even without a differential matching ratio, states have demonstrated over the past 20 years a willingness to shift expenditures from institutional to HCB services. Between fiscal years 1997 and 2007, the percentage of total long-term care expenditures devoted to home and community-based services increased from 24 percent to 42 percent.²² The shift toward home and community-based services has been even more dramatic within the I/DD services sector. Here, the proportion of Medicaid LTC expenditures committed to HCB services grew from 14.5 percent in 1992 to 63.1 percent in 2007.²³ Nonetheless, there remain thousands upon thousands of individuals with chronic disabilities who need and want home and community-based supports. And, unlike past years, states have few, if any, unmatched state and local dollars available to draw down additional federal funds for HCB services. So, common sense suggests that a higher FMAP rate for HCB services and a correspondingly lower FMAP rate for NF, IMD, and ICF/MR services might induce states to accelerate the movement toward home and community-based long-term services.

But, will the Obama Administration and Congress be amendable to increasing state FMAP rates to accelerate the shift toward home and community-based services – especially on top of the substantially (albeit temporary) increases in FMAP rates approved by Congress earlier in the year as part of the economic stimulus legislation. As CBO’s analysis suggests, there are sizeable upfront costs associated with pursuing such a strategy, especially if, as is likely, the enhanced FMAP rate is applied to both current and newly enrolled recipients of HCB services but only to newly enrolled institutional residents. Will Congress and the Administration be willing to shoulder the additional billions of dollars in program outlays when the federal deficit already is projected to reach an unprecedented \$1.8 trillion this fiscal year, plus at least a trillion dollars in each of the following two fiscal years?

In a world of finite resources, dollars committed to one type of systemic improvement aren’t available to address other pressing needs

There is no question that low pay scales and inadequate benefits are major contributors to high turnover and vacancy rates as well as low morale among community care workers. Nor can it be reasonably argued that finding ways of building a stable, well-trained and fairly compensated labor force isn’t critical to offering consistently high-quality home and community-based supports to persons with disabilities. But, work force stability is just one of numerous challenges facing state and local disability service systems – to name just one, meeting the extensive backlog of needs among un-served and under-served individuals. In a world of finite resources, dollars committed to one form of systemic improvement are not available to address other competing systemic priorities. It makes more sense, therefore, to grant each state the latitude to tailor its mix of system improvement strategies to locally perceived needs and priorities, rather than attempting to tilt cost sharing policies in favor of a particular type of systemic reform.

Create a worker-financed insurance program to supplement services paid for through public programs. The central aim of the CLASS Act (as well as an alternative, private insurance plan sketched out in the CBO report) is to create personal savings that are available to cover long-term service costs. The operational features of the two plans differ in significant ways. The CBO plan would require all workers to set aside a given percentage of their salaries/wages for the purchase of a long-term care insurance policy once they reach retirement age. In contrast, workers would be allowed to opt out of participating in the CLASS plan. In addition, qualifying CLASS participants would make voluntary contributions (at a flat monthly rate) and receive benefit checks directly from the federal government (rather than via private insurance payments) based on the comparative severity of their disabling conditions. The underlying intent of both measures, however, is to help workers avoid having to impoverish themselves should they experience a significant disability and, thereby, take some of the financial pressure off of the federal-state Medicaid program.

Whether a voluntary plan would result in an actuarially sound program over the long haul is open to debate. Supporters of the CLASS legislation report that preliminary studies suggest that the number of workers choosing to opt out would be small enough to ensure sound financing of the plan; and, furthermore, the program eventually could operate with few if any taxpayer subsidies. Of course, the studies upon which these predictions are based were conducted during much better economic times and it seems reasonable to ask: would the results be the same in the current economic environment where the unemployment rate is rising rapidly and many workers are worried about scraping together enough monthly income to pay for the necessities of life. Furthermore, like the CBO option, presumably CLASS plan contributions and benefit payments would be reflected in the federal budget and, during the early years of the program, are likely to contribute to an already huge federal deficit.

Savings plans designed to help workers accumulate resources to offset the potential costs of a severe disability largely ignore the long-term support needs of persons with developmental disabilities

The major problem, however, with both approaches is that, unlike the Social Security Disability Insurance program, dependents of insured workers who experience a qualifying disability – including sons and daughters with developmental disabilities – would not be eligible to receive benefits. On paper at least, working individuals with developmental disabilities could qualify for benefits if they met the applicable disability and minimum years of participation tests. However, given the restricted work schedules and low wages of most workers with developmental disabilities, the required monthly premiums would be prohibitive, especially if they were based on a flat monthly rate (as in the CLASS Act), rather than calculated as a percentage of wages. Some children and adults with developmental disabilities might gain residual benefits from long-term disability payments to the primary wage earner in their home. But, by far, the principal beneficiaries of the legislation would be workers (primarily middle-aged and older workers) who experience a severe disability later in life. Individuals with intellectual and developmental disabilities, along with persons experiencing a disability early in their work careers, would remain almost entirely dependent on Medicaid as their payment source for long-term services and supports.

Consolidate responsibility for financing and managing acute and long-term supports to dual eligibles. For low-income individuals who become severely disabled later in life, a solid case can be made for merging responsibility for health care and long-term supports. The 8.8 million Medicare beneficiaries who also are entitled to full Medicaid benefits are among the sickest and poorest individuals covered by the two programs. They represented 18 percent of Medicaid beneficiaries but accounted for almost half of all program costs in 2005.²⁴ Existing incentives to shift costs between the

two levels of government lead to the inefficient use of resources and poor overall coordination of care. And, furthermore, for a large proportion of this population, the cause of chronic disability is directly linked to an underlying health condition and, consequently, the coordination of health care and long-term supports is vitally important.

The profile of dual eligibles with developmental disabilities, however, is much different. They are considerably younger, on average; furthermore, the underlying cause of their disabilities is either unknown or of genetic or metabolic origins and, as such, not susceptible to traditional medical interventions. The rationale for consolidating acute and long-term services under a medical care umbrella, consequently, is considerably weaker for this segment of dual eligibles. Indeed, past experience with operating services to persons with developmental disabilities as part of the overall medical care system has been disastrous, because the most pressing need among younger persons with disabilities typically is assistance in “getting a life” rather than “getting well.” Moreover, the net effect of transferring responsibility for managing long-term services to the federally administered Medicare program would be to create a dual system of long-term services for persons with developmental disabilities, based solely on a factor unrelated to the support needs of the person (i.e., whether or not one qualifies for Medicare as well as Medicaid benefits).²⁵ Such a dual service system would lead to the inefficient use of scarce resources and almost inevitably create gaps and inequities in services across the two systems.

Cross-Cutting Themes

Two recurring, intertwined themes emerge from this review of pending federal long-term services reform proposals. These themes deal with: (a) accommodating the differing support needs of various LTC sub-populations; and (b) addressing the complexities of achieving positive, sustainable changes within a program in which the federal government and the states share financing and managerial responsibilities.

First, the reform proposals in general devote little attention to accommodating the unique needs of children and adults with lifelong disabilities and the state-local systems through which they receive supports. None of the proposals discussed above, except the Direct Support Professionals Fairness and Security Act, were initially designed to address issues facing the developmental disabilities service sector. And, while a few of these measures have been modified in recent years to extend benefits to the I/DD population, for many individuals with intellectual and developmental disabilities – especially persons with complex support needs – the resulting programs would have a limited impact.

In our zeal to create closer bonds between the aging and disability communities, we should not lose sight of the enormous diversity of needs among the 10 million Americans with severe, chronic disabilities

Impact of Health Policy Bias

An illustration of the ways in which efforts to improve long-term services can be derailed by the overriding health reform perspective can be found in current attempts to develop national home and community-based performance indicators.

In 2005, Congress directed the U.S. Secretary of Health and Human Services, acting through the Agency for Healthcare Research and Quality (AHRQ), to develop a set of national performance indicators for Medicaid-funded home and community-based (HCB) services. The legislation also directs the Secretary to assess HCB service outcomes, especially outcomes related to the impact such services have on the health and welfare of Medicaid recipients, by September 2010.

Work on developing the required performance indicators is still underway within AHRQ. But, agency officials already have decided that a single indicator set should: (a) be designed to apply to all Medicaid recipients of HCB services; and (b) limited to measure of health and preventable incidents. Conversely, AHRQ has decided to exclude from the initial indicator set measures of client satisfaction and quality of life, despite the diverse characteristics and needs of HCBS recipients and the fact that for most of them the primary service goal is to live a fulfilling, productive and inclusive life.

The basic aim of most of these proposals (plus many other pending or proposed measures not discussed here) is to promote home-based care for frail elders and other adults with physical disabilities, either by: (a) inducing workers to save systematically throughout their work careers so they can afford to purchase long-term supports (directly or via insurance payments) late in life; or (b) by promoting the coordinated delivery of health care and long-term supports for individuals with chronic conditions. The co-management of acute care and long-term supports, as noted above, makes eminent sense in the case of frail elders, where chronic health conditions almost always are the direct cause of the physical and/or cognitive impairment; but, the same rule does not apply to individuals who acquire a severe disability at a younger age – especially when the disability occurs during the perinatal period and has lifelong consequences. The health care needs of the vast majority of younger persons with developmental disabilities are not substantially different than those of their non-disabled age-group peers. There are unique challenges associated with delivering health services to individuals with significant cognitive and behavioral needs; and, consequently, coordination of health and long-term care benefits is important. But, these accommodations are insufficient reasons to return to a medical model of managing long-term supports for persons with lifelong disabilities. We've been down that path before and it is clear that the medical model simply doesn't work – and is inappropriate – for the vast majority of younger persons with disabilities.

Frail elders and younger individuals with disabilities share common goals. Paramount among these goals is to shatter the social isolation, discrimination and neglect that too often entrap people with disabilities by offering them opportunities to live inclusive, dignified and self-directed lives in communities of their choice. To accomplish these shared goals, collaboration between the aging and disability communities is essential. But, in our zeal to create stronger bonds between these two communities, we should not lose sight of the enormous diversity of needs among the 10 million Americans with severe chronic disabilities and the related importance of tailoring supports to the needs of each individual. Younger people with disabilities have distinctive needs. Children with disabilities, for example, must acquire – often painstakingly and with extraordinary assistance – the basic social, emotional and behavioral skills necessary to become productive members of society. As they leave school and reach adulthood, vocational training, counseling and job placement services frequently are required to help them obtain and retain employment. Moreover, many adults with lifelong disabilities need a supported living environment in which they have access to social supervision and assistance on an intermittent or, in some cases, round-the-clock basis, as well as help in building rich, varied lives within their respective communities.

For the most part, the above-mentioned services are foreign to state/local aging service systems. In recognition of this fact, most states have elected to operate separate service delivery systems for elders and adults with physical disabilities, persons with intellectual and developmental disabilities, and persons with severe and persistent mental illnesses. By doing so, they are able to build the specialized expertise necessary to address the distinctive needs of each of these sub-populations and organize a constellation of interventions and supports molded to the particular needs of each target group.

In recent years, aging and disability services have been consolidated in several states. Reduced fragmentation, the elimination of duplicative staff functions, and lower administrative costs are often cited as the main benefits of these consolidations. But, unless service integration initiatives are carefully implemented and accompanied by a strong commitment to improve service quality and oversight for all eligible persons (which often they are not), these reorganizations lead to an attrition of expertise, as agency staff are asked to assume new, unfamiliar roles working with groups of people they have little or no experience in assisting. The inevitable result is a reduced sensitivity to the distinctive needs of younger persons with disabilities, who make up only a small portion of the overall target population, and a dissipation of leadership at the state and local level within the I/DD sector.

Second, one of the common flaws of many pending long-term reform proposals (including some of the measures discussed above) is that they fail to take sufficient account of the differences among the states and allow them to craft their own, unique strategies for expanding access to and improving the quality of services. Medicaid is a federal-state program in which responsibility for policymaking and financing is shared between the federal government and the states. During FY 2006, states and localities

spend \$135 billion on Medicaid services, or approximately 43 percent of overall program outlays. Yet, as Allan Weil pointed out in a recent commentary on national health reform,

... states are often treated [by federal policymakers] as if they are incapable of or uninterested in designing and administering effective programs. In particular, states are viewed as insufficiently attentive to the needs and rights of program enrollees.²⁶

There are sound reasons for skepticism. States often go to extraordinary lengths to maximize federal cost sharing, and clearly in a few instances the resulting funding schemes are indefensible. But, as Weil notes, criticisms of state behavior frequently are allowed to mask a larger truth – i.e., “states have at least as much at stake as the federal government when it comes to administering effective health care programs.”²⁷

Indeed, in the long-term services arena, states have spearheaded the shift toward home and community-based support systems over the past quarter century. Years before the federal government began to actively promote the development of community-based alternatives to institutional care, the states were leveraging Medicaid dollars to create community support systems for individuals with disabilities – often with little encouragement (and periodic hostility) from the federal bureaucracy. The federal government’s post-Olmstead initiatives unquestionably have allowed states to accelerate the movement of Medicaid dollars from institutional to HCB services. But, the accelerated pace of change would not have been possible without the foundations which states and localities laid prior to the late 1990s.

Many national long-term services reform proposals fail to take into account the differences among the states and, as a result, contain legislative strategies that are not well suited to the purposes they are designed to achieve

The Medicaid home and community-based waiver authority clearly illustrates the upside as well as what many view as the downside of a federal-state partnership. During FY 2005, over one million individuals received home and community-based waiver services, up from 688,000 in FY 1999. Meanwhile, during this same period, federal-state HCBS waiver expenditures rose from \$16 billion to \$23 billion dollars.²⁸ Section 1915(c) waiver expenditures and utilization on behalf of persons with developmental disabilities have grown at an even faster pace. The number of enrollees in I/DD waiver programs more than doubled between 1997 and 2007 (growing from 221,909 to 501,489), while expenditures on behalf this segment of the waiver population more than tripled (growing from \$6.0 billion to \$20.3 billion).²⁹

By any reasonable measure, the Section 1915(c) waiver authority has been one of the most successful components of the federal-state Medicaid program in recent years. But, the key to its success – i.e., the flexibility it affords states to craft strategies tailored to their own unique needs and resources – results in significant state-to-state variations in the types and ranges of services to, and expenditures on behalf of, persons with chronic disabilities. During FY 2005, for example, the number of individuals with developmental disabilities enrolled in HCBS waiver programs per 100,000 in the general population varied from a low of 60 in Nevada to a high of 483 in North Dakota (with a median of 150 for all states); meanwhile that same year, per capita expenditures for I/DD waiver services ranged from a low of \$14,914 in the District of Columbia and \$18,683 in North Dakota to highs of \$74,951 in Maine and \$73,563 in Delaware (compared to a median figure of \$39,679 for all states).³⁰

These variations are the products of a variety of underlying forces that have shape the direction and pace of service development in each state. Many individuals with disabilities, their family members as well as disability advocates, however, find these variations very frustrating. Their support for legislation mandating open-ended access to home and community-based services is understandable. But, the reality is that as long as state governments are constitutionally required to balance their budgets and federal law obligates states to assume a major portion of Medicaid program costs, these variations are likely to persist. The choices boil down to federalizing long-term care benefits, possibly by shifting Medicaid benefits to the Medicare program, or advocating more effectively for change within state capitals across the nation.

Conclusion

The purpose of this paper has been to explore the relationship between President Obama's efforts to reform the national health care system and the future financing and delivery of long-term services and supports to persons with intellectual and developmental disabilities. In particular, the paper examines a variety of proposals to revamp federal long-term care policies in the context of a global health reform measure, and illustrates the ways in which each strategy might impact the I/DD population. A second paper will explore in greater depth the foundational strategies for restructuring health care delivery systems and compare and contrast these strategies with changes that need to be pursued within the long-term service sector. The emphasis in this latter paper will be on identifying similarities and differences in reform strategies applicable to the health care sector versus the long-term service sector.

At the moment, the continuing deterioration in the states' fiscal situation casts a dark shadow over publicly-funded human services programs of all types, including services to persons with intellectual and developmental disabilities. The National Conference of State Legislatures projects that the states collectively will need to slash an additional \$47.4 billion out of their budgets for the current fiscal year (FY 2009) – and these cuts will come on top of \$40.3 billion in previously approved reductions. The imbalance

between revenues and expenditures, moreover, is expected to widen next fiscal year when the states will have to close an estimated \$84.3 billion funding gap.³¹

Opinions vary regarding the extent to which the federal economic stimulus legislation will allow states to fend off debilitating spending cuts. Raymond Scheppach, Executive Director of the National Governors' Association, estimates that the eventual state budget shortfall for FY 2009-11 will approach \$250 billion. Spending cuts and tax and fee increases of this magnitude, he notes, will have a "huge negative impact on the [national] economy," leading to a "longer and deeper" recession. The \$100 billion of flexible money included in the economic stimulus package, he estimates, will fill in about 40 percent of the shortfall. However, states still will be under considerable pressure to eliminate ineffective programs and streamline many others.³²

It is not clear at the moment whether the Obama Administration and Congress will pursue major changes in long-term services policies, either separately or as part of the forthcoming health reform legislation. The present analysis, however, suggests that changes along the lines of existing LTS reform proposals will offer states few opportunities to improve services and supports to the I/DD population. Yet, the impact of the continuing rounds of budget cuts currently occurring in many state DD programs underscores the risks of adopting a strategy that attempts to preserve the status quo regardless of the resulting deterioration in service access and quality.

Difficult times call for bold actions. As Michigan Governor Jennifer Granholm recently put it, "a budget deficit is a terrible thing to waste."³³ This is not the first occasion when economic hard times have forced state DD service systems to re-assess spending patterns in the light of a serious budgetary shortfall. Sometimes a budget crisis allows state/local officials and provider agency administrators to take steps that would not be feasible in a more favorable fiscal climate. For example, census reductions in state-run DD institutions peaked during the late 1980s and early 1990s in part because states faced tight budgets and were forced to make tough choices in order to achieve system-wide economies. In some states, opportunities to economize may take a different form today than they did 10 or 20 years ago. But, whether the focus is on transitioning individuals to less costly, more integrated community living settings or helping young adults to achieve gainful employment, the principal is the same – the focus needs to be on pursuing person-centered strategies that make more effective use of scarce resources while still safeguarding the health and well-being of all recipients of long-term supports. Furthermore, any near-term policy changes aimed at surviving the financial crisis must be designed to build tomorrow's service delivery system around the core principles of individualization, community integration, independence, productivity and self-direction. With these longer term goals in mind, the emphasis should be on expanding opportunities for employment, promoting self-sufficiency, utilizing generic housing options (rather than specialized residential facilities) wherever possible, and supporting people with lifelong disabilities to map out and control their own lives.³⁴

We live in transformational times and, while shielding highly vulnerable people from funding reductions as best we can has to be the first order of business, we can't afford

to ignore the broader policy changes that are emerging from the nation's capital. The President's health reform initiative has the potential to alter in fundamental ways the future financing of long-term supports for children and adults with developmental disabilities. And, should major revisions in long-term services polices be left out of health reform legislation, they almost certainly will be addressed in subsequent legislation to rein in the growth in federal entitlement spending.

Developmental disabilities stakeholders, therefore, can't afford to sit passively on the sidelines and assume that long-established spending and service delivery patterns will resume once the economy recovers and state coffers once again are flush. Instead, those committed to advancing the interests of persons with lifelong disabilities – self-advocates, parents, professionals, service providers, academicians, and state and local officials – need to speak out on the important policy issues of the day. Hopefully, this paper (and the forthcoming companion piece) will help prepare I/DD stakeholders to become active participants in the unfolding debate surrounding the future of Americans with lifelong disabilities.

End Notes

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⁴ "The Healthy Americans Act Section by Section," December 8, 2006 (<http://wyden.senate.gov/issues/Healthy%20Americans%20Act/sectionbysectionfeb09.pdf>).

⁵ Remarks by the President upon signing the American Recovery and Reinvestment Act (H.R. 1; P.L. 111-5), Phoenix, Arizona, February 17, 2009. Available online at: http://www.whitehouse.gov/the_press_office/Remarks-by-the-President-and-Vice-President-at-Signing-of-the-American-Recovery-and-Reinvestment-Act/.

⁶ Steinbrook, Robert, "Health Care and the American Recovery and Reinvestment Act," *The New England Journal of Medicine*, published at www.nejm.org, February 17, 2009.

⁷ President Obama's February 24, 2009 address to the U.S. Congress (http://www.whitehouse.gov/the_press_office/Remarks-of-President-Barack-Obama-Address-to-Joint-Session-of-Congress/).

⁸ White House Office of Management and Budget, *A New Era of Responsibility: Renewing America's Promise*, Office of Management and Budget: Washington, D.C., February 26, 2009.

⁹ Press briefing by OMB director Peter Orszag and Council of Economic Advisors chairman Christine Romer on the President's budget plan, The White House, February 26, 2009 (http://www.whitehouse.gov/the_press_office/Press-Briefing-by-OMB-Director-Peter-Orszag-and-CEA-Chair-Christina-Romer/).

¹⁰ Kaiser Commission on Medicaid and the Uninsured and the Urban Institute, “Medicaid Enrollees and Expenditures by Enrollment Group, 2005” in Kaiser Fast Fact, Washington, D.C. and Menlo Park, California: Henry J. Kaiser Family Foundation, 2008 (<http://facts.kkf.org/chart.aspx?ch=465>).

¹¹ **Call for Action: Health Reform 2009**, Ibid, page79.

¹² Opening remarks by Senator John D. Rockefeller at a public hearing on “The Role of Long-Term Care in Health Reform” held before the Subcommittee on Health, Senate Finance Committee, March 25, 2009.

¹³ Many of the following measures are likely to be re-introduced during the 111th Congress. If so, they will be assigned new bill numbers and possibly include some modifications aimed at addressing perceived weaknesses.

¹⁴ These issue papers are available on the committee’s website at: Improving Patient Care and Reducing Costs:

<http://finance.senate.gov/sitepages/leg/LEG%202009/042809%20Health%20Care%20Description%20of%20Policy%20Option.pdf>; Expanding Health Care Coverage:

<http://finance.senate.gov/sitepages/leg/LEG%202009/051109%20Health%20Care%20Description%20of%20Policy%20Options.pdf>; and Financing Health Reform:

<http://finance.senate.gov/sitepages/leg/LEG%202009/051809%20Health%20Care%20Description%20of%20Policy%20Options.pdf>

¹⁵ Congressional Budget Office, **Budget Options, Volume 1, Health Care**, Chapter 10, Long-Term Care, pp. 193-204. Available online at <http://www.cbo.gov/doc.cfm?index=9925>.

¹⁶ U.S. Congressional Budget Office, **CBO Budget Options: Volume I Health Care**, U.S. Congressional Budget Office, December 2008.

¹⁷ Livermore, Gina, David Stapleton and Henry Claypool, “Costs and Benefits of Eliminating the Medicare Waiting Period for SSDI Beneficiaries,” Disability Policy Brief No. 09-02, Center for Study of Disability Policy, March 2009. Available on line at <http://www.mathematica-mpr.com/publications/PDFs/disability/medicarewaitperiodbr09-02.pdf>.

¹⁸ <http://www.whitehouse.gov/agenda/disabilities/>.

¹⁹ A total of \$211 million is set aside for this purpose in the FY 2010 budget blueprint which the President submitted to Congress on February 26, 2009.

²⁰ Kaiser Commission on Medicaid and the Uninsured, “Medicaid Home and Community-Based Service Programs: Data Update,” December 2007, page 7. Available on-line at www.kff.org.

²¹ Hemmings, C.P, Tsakanikos, E., Underwood, L., Holt, G. & Bouras, N. (2008), Clinical Predictors of Severe Behavioural Problems in People with Intellectual Disabilities Referred to a Specialized Mental Health Service,” **Social Psychiatry and Psychiatry Epidemiology**, 43, pp. 824-830.

²² Burwell, Brian, Kate Sredl and Steve Elkins, “Medicaid Long-Term Care Expenditures in FY 2007,” Thomson Reuters Healthcare, September 26, 2008.

²³ Ibid.

²⁴ Holahan, et al., Ibid.

²⁵ The vast majority of persons with developmental disabilities qualify for Social Security and, following a 24- month waiting period, Medicare benefits based on the earning records of their father or mother. In

Social Security parlance, these individuals are referred to as Adult Disabled Child (ADC) beneficiaries. If all health and long-term services to dual eligibles were to be transferred to the Medicare program, ADC beneficiaries would receive long-term services paid for and managed through the Medicare program, while all other qualified children and adults with developmental disabilities would continue to receive long-term services benefits through the federal-state Medicaid program.

²⁶ Weil, Alan, "A New Approach to the State-Federal Relationship in Health," *Health Affairs*, Vol. 28, No. 2, January 2009.

²⁷ Ibid.

²⁸ "Medicaid 1915(c) Home and Community-Based Service Program: Data Update," Issue Brief, Kaiser Commission on Medicaid and the Uninsured, December 2006. 2005 expenditure and utilization data obtained from statehealthfacts.org at <http://www.statehealthfacts.org/comparecat.jsp?cat=4>.

²⁹ Lakin, K. Charlie, Robert Prouty, Kathryn Alba, and Naomi Scott, "Twenty-Five Years of Medicaid Home and Community Based Services (HCBS): Milestones Reached in 2007," *Intellectual and Developmental Disabilities*, Vol. 46, No. 4, August 2008, pp. 325-328.

³⁰ Prouty, Robert W., Gary Smith, and K. Charlie Lakin, *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2005*, Institute on Community Integration, Research and Training Center on Community Living, University of Minnesota: Minneapolis, July 2006, pp. 77 and 84.

³¹ "Update on State Budget Gaps: Still Bleak," NCSL News, National Conference of State Legislatures, February 3, 2009 (<http://www.ncsl.org/programs/press/2009/pr020409gapupdate.htm>)

³² "How Much of a Difference Will the Economic Stimulus Package Make to the States," stateline.org, February 17, 2009 at <http://www.stateline.org/live/details/story?contentId+3777039>.

³³ Quoted during an address by Peter Harkness, entitled "Unsustainable Trends: Across a Wide Range of Activity, Existing Trends Cannot Continue Much Longer, Changes are Coming That Will Have a Profound Effect on Government at All Levels," delivered at the 2008 Annual Conference of the National Association of State Directors of Developmental Disabilities Services, Alexandria, Virginia, November 14, 2008.

³⁴ For an expanded discussion of forward-looking state budget cutting strategies, see "How to Manage in an Economic Downturn," National Association of State Directors of Developmental Disabilities Services, December 2008. This paper is available online at <http://www.nasddds.org/pdf/HowToManageInAnEconomicDownturn.pdf>.