

Policy Insights

Will National Health Reform Help Individuals with Developmental Disabilities?

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 bulletin, 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.

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.



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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 variety of proposed reforms in health care policy, little attention has been focused on the impact such legislation may have on future Medicaid funding of services to persons with developmental disabilities.

The purpose of this *Policy Insights Bulletin* is to assess the impacts national health reform legislation may have on existing arrangements for financing and delivering specialized services to persons with developmental disabilities. More specifically, the report discusses the ramifications of possible modifications in federal long-term policies – either as part of a global health reform measure or separately – for persons with developmental disabilities. A later bulletin will examine the similarities and differences in underlying strategies for

restructuring health care and long-term services in the United States.

Background

A commitment 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.

President Obama has backed up his promise to reform the health care system by including approximately \$150 billion in new health care funding in a recently enacted economic stimulus measure 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 care services to all Americans. These initiatives are characterized by Administration officials as a down payment on the President's promise to reform the American health care system.

The "American Recovery and Reinvestment Act" (ARRA; P.L. 111-5), which President Obama signed into law on February 17, 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. Of the total funds included in the economic stimulus measure, about \$144 billion, or 18 percent, is targeted to helping state and local governments weather the effects of steep 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 though enhanced federal financial participation in the cost of Medicaid services. The higher 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.

The net effect is that federal medical assistance participation (FMAP) rates in all states will rise by 7.5 to 14.0 percentage points over the next two fiscal years. Besides enhanced Medicaid payments, the ARRA includes \$63 billion in funding for other federal health care programs.² 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 record and other 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.

For a variety of reasons, the prospects for fundamental changes in the American health care system appear to be better than they have been for several decades. Indeed, even the grim economic outlook seems to tilt in favor of reform since most budget experts believe that current health spending patterns are unsustainable and, consequently, reining in the growth of health care outlays is critical to revitalizing the nation's economy and stabilizing federal and state budgets over the long term. At the same time, everyone recognizes that reaching agreement on the appropriate mix of reform strategies will be challenging. There are simply too many competing interests to assume that health reform legislation will slip through Congress without some serious, hard-fought battles. 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 moment. Among the many unanswered questions is: how will long-term supports for persons with intellectual, 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 strategy 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 system, Obama's stated aim is to provide affordable, accessible health care for all Americans.

Enacting health reform legislation will require an act of political jujitsu rarely achieved in the annals of American history

Learning from failed reform efforts of the past (especially the demise of the Clinton health plan in the mid-1990s), the President has elected to allow Congress to take the lead in developing health care reform legislation. Not surprisingly, given the fact that Democrats hold comfortable majorities 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 (HELP) Committee, and Senator Max Baucus (D-MT), chairman of the Senate Finance Committee, have been developing their own health reform measures, with the aim of introducing separate, but

coordinated 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.

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 overarching goal is to ensure all (or at least most) Americans access to health care. The general objectives are to create a health care system which:

- Guarantees 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.
- Promotes 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.
- Institutes 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.

All of the major health reform plans advanced to date seek to accomplish most or all 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 as part of a global health reform measure.

Reining in Entitlement Spending

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.⁵ The White House released the broad outline of the President’s revised 10-year budget plan to accomplish these objectives on February 26⁶ and later added some details in the FY 2010 budget he submitted to Congress in early May. The current plan relies on four basic strategies to reduce deficit spending – i.e., restoring the vitality of the nation’s 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 federal programs government-wide.

During a late February press briefing on the new Obama budget, Office of Management and Budget Director, Peter Orszag said that reforming the health care system is “... the single most important thing we could do ...” to eliminate deficit spending.⁷ Extensive evidence, he added, 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 now account for over \$700 billion of federal expenditures per year and nearly a trillion dollars when state Medicaid matching

Health Reform Goals

- Universal access to care
- More cost-efficient & affordable care
- Enhanced system-wide efficiency to eliminate unnecessary costs

contributions are taken into account. 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 Medicaid outlays. Expenditures on behalf of persons with developmental and other disabilities make up a disproportionate share of total Medicaid spending. In 2005, non-elderly persons with disabilities constituted 14 percent of Medicaid beneficiaries but accounted for 42 percent of all program outlays.⁸ 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 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 released by Senate Finance Committee Chairman Max Baucus last December points out that the existing long-term care system “... is expensive, inefficient and does not encourage the delivery of high-quality care.”⁹ 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 past 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;

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.

In introducing 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

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

\$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.”¹⁰ 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 unsettled on the eve of the health reform debate in Congress.

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

Should Congress and the Administration decide to pursue major changes in long-term services policy as part of health reform legislation, it seems reasonable to presume that they will employ at least some of the basic strategies currently under consideration. Therefore, to gain a sense of the impact these approaches might have on future specialized services for persons with developmental disabilities, let us next examine various long-term services reform options that have been advanced.

- **Enhance state flexibility under the existing home and community-based state plan coverage option.** Under this approach, existing statutory impediments to electing the Section 1915(i) HCBS state plan option would be removed. A bill to accomplish this purpose, entitled the “Empowerment at Home Act (S. 3347; H.R. 7212), was introduced last year by Senator John Kerry (D-MA) and Representative Edward Markey (D-MA). It would: (a) replace the current income

ceiling on qualifying for HCB services under Sec. 1915(i) (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 designate population groups to receive targeted case management services under existing law; and (d) make a number of other changes in present law to encourage the use of home care options. Several of the statutory changes proposed in the Kerry/Markey bill also are included in an options paper recently released by the Senate Finance Committee. [N.B., The purpose of this options paper is to assess the degree of support for various statutory reforms as the committee seeks to reach agreement on the mix of provisions which should be included in a comprehensive health reform measure. Consequently, the options outlined in the paper are not necessarily supported by the committee as a whole or any of its individual members.]

For persons with developmental disabilities, a statutory mandate must encompass a wide range of community supports if effective alternatives to institutional care are to be fashioned by the states

There are serious defects in the existing statutory authority governing the Section 1915(i) coverage option. Although states have been permitted to add this coverage to their Medicaid plans since January 1, 2007, few states have done so thus far – and all of the participating states have chosen to target such services to narrowly defined groups of potential recipients. Unquestionably, states would be more inclined to elect this coverage option if the previously mentioned impediments were to be removed from the law. A Medicaid 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 would lead to a sizeable increase in the overall number of enrollees in Medicaid-financed HCB services. Faced with declining revenues and increasing demand for social and health services, most states are desperately trying to keep social safety net programs intact as they formulate their FY 2009-10 budgets. The temporary increase in FMAP rates and the other forms of state-local aid included in the new economic stimulus legislation should help many states to avoid

the most devastating spending cuts. But, given the ravages of the recession, in most states significant expansions in HCB services probably will have to be postponed until an economic recovery is well underway.

- **Offer 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, later, Section 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 growth 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 and, in the case of the Section 1915(i) authority, avoid adopting this coverage option for any potential target group.

From an I/DD perspective, a mandate encompassing all HCB services, however, is preferable to a mandate applied to personal/attendant care services only, such

as the one called for in the Community Choice Act (CCA), a measure re-introduced earlier this year by Senator Tom Harkin and Representative Danny Davis.¹¹ Under the most recent iteration of the 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, some individuals with developmental disabilities would benefit from expanded access to attendant services and supports were this legislation to be enacted into law. But, the statutory revisions contained in the Community Choice Act would leave unaddressed many needs of persons with more, complex disabilities. Ample evidence of this fact can be found in existing home and community-based waiver programs which states operate for persons with mental retardation and 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 state officials have learned over the years that a broad menu of community supports is required if sustainable, high-quality alternatives to institutional care are to be created for the entire spectrum of eligible persons with 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.¹² The CCA's emphasis on affording persons with disabilities expanded opportunities to self-direct their supports is praiseworthy – as is the provision requiring services to be furnished in fully integrated community settings. In the case of persons with developmental disabilities, however, 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 Medicaid matching rate for home and community-based 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 for direct support professionals in the case

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

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 SCHIP costs (whether eligible children are enrolled in the state's Medicaid program or in private health insurance plans), states have been 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 options paper,¹³ would have a significant impact on state decision-making in this area. 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

out-year costs they will be obligated to absorb and, consequently, can be expected to proceed cautiously in undertaking new initiatives in which they are required to assuming a growing share of program costs.

But, even assuming a positive response from the states to a differentially higher matching rate, 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?

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 benefit program to supplement services paid for through public programs.** The “Community Living Assistance Services and Supports (CLASS) Act” (S. 1758 (Kennedy); H.R. 7212 (Dingell)) is an example of this approach. This bill would create a voluntary, national, premium-based disability insurance program outside of Medicaid and Medicare. Workers would be automatically enrolled, but would have the option of declining to participate. Participants would be required

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

to pay monthly premiums and, should they become disabled, the program would pay them cash benefits to purchase non-medical services and supports. A two-tiered system of benefits would be created. To qualify for benefits, a Tier 1 beneficiary would have to have paid premiums for at least five 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 such beneficiaries would have to be unable to perform three or more activities of daily living. Both Medicaid and non-Medicaid beneficiaries would be eligible to participate.

An alternative approach is outlined in a recent CBO analysis of health reform options.¹⁴ Under this approach, all workers would be required to contribute a set percentage of their salary/wages to an individual savings account, the balance of which would be used when the participant reaches age 65 to purchase the most generous private long-term care insurance policy available. The program would apply only to workers (not unemployed spouses or dependents) and would be phased in over a period of years, beginning in 2012. Individual contributions to these savings accounts would receive favorable tax treatment. The estimated federal cost of the program – almost entirely in the form of lost payroll and income tax revenues – would be \$34 billion over five years and \$214 billion over 10 years.

The central aim of both CBO’s private insurance option and the provisions of the CLASS Act is to create personal savings that are available to cover long-term service costs. Despite significant differences in the operational features of the two plans, both approaches are intended to help workers avoid having to impoverish themselves should they experience a significant disability. One of the common aims of both approaches is to reduce federal-state Medicaid outlays in future years.

Whether a voluntary plan would result in an actuarially sound program over the long haul is open to debate. But, from an I/DD perspective, the main problem 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 receive benefits if they met all of the qualifying requirements. However, given the restricted work schedules and low wages of most workers with developmental disabilities, the 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. 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 developmental disabilities, along with persons experiencing a disability early in their work careers, would remain dependent on Medicaid as their payment source for long-term services.

- **Consolidate responsibility for financing and managing acute and long-term supports for 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

Federalizing services to dual eligibles would bifurcate the present DD service system and raise the specter of operating services under a medical model

of all program costs in 2005.¹⁵ 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. For this reason, Congress is considering several approaches to synchronizing the financing and delivery of Medicare and Medicaid services to dual

eligibles, including the creation of a new waiver/demonstration authority and the establishment of a new unit within the Centers for Medicare and Medicaid Services to spearhead such cross-program initiatives.¹⁶

The profile of dual eligibles with developmental disabilities, however, is much different than

beneficiaries who become disabled later in life. 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).¹⁷ 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 differing support needs of various LTC sub-populations; and (b) addressing the complexities of achieving sustainable changes within a program in which the federal government and the states share financing and managerial responsibilities.

First, existing long-term services reform plans 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.

The basic aim of most of these proposals 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. Yes, there are unique challenges associated with serving 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 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

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

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 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, the management of aging and disability services has 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.

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

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 improving service access and quality. 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 recently pointed out,

... 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.¹⁸

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.”¹⁹

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, states were leveraging Medicaid dollars to create community supports 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 hasten 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.

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.²⁰ 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 MR/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).²¹

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 range 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 MR/DD waiver services ranged from a low of \$14,914 annually 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).²²

These variations are the products of a variety of underlying forces that have shaped the directions 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 will persist. The choices boil down to federalizing long-term care benefits, possibly by shifting Medicaid long-term care benefits to the Medicare program, or advocating more effectively for changes at the state level.

Conclusion

At the moment, the continuing deterioration in the fiscal position of many states casts a dark shadow over publicly funded human services programs of all types, including services to persons with developmental disabilities. The National Conference of State Legislatures projects that states collectively will need to slash \$47.4 billion more 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.²³

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 make up about 40 percent of the shortfall. However, states still will be under heavy pressure to eliminate ineffective programs and streamline many others.²⁴

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 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."²⁵ 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 simultaneously 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.²⁶

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 individuals 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

¹ Braddock, David, Richard Hemp and Mary C. Rizzolo, *The State of the States in Developmental Disabilities: 2008*, American Association on Intellectual and Developmental Disabilities: Washington, D.C., 2008.

² 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.

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

⁵ President Obama's February 24, 2009 address to the U.S. Congress (www.whitehouse.gov/the_press_office/Remarks-of-President-Barack-Obama-Address-to-Joint-Session-of-Congress/).

⁶ 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.

⁷ 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 (www.whitehouse.gov/the_press_office/Press-Briefing-by-OMB-Director-Peter-Orszag-and-CEA-Chair-Christina-Romer/).

⁸ 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 (facts.kkf.org/chart.aspx?ch=465).

⁹ *Call for Action: Health Reform 2009*, Ibid, page 79.

¹⁰ 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.

¹¹ Press release by Senator Tom Harkin, March 24, 2009. Available online at harkin.senate.gov/pr/p.cfm?i=310417.

¹² 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.

¹³ See page 52 of Senate Finance Committee's options paper on expanding health care coverage at: finance.senate.gov/sitepages/leg/LEG%202009/051109%20Health%20Care%20Description%20of%20Policy%20Options.pdf.

End Notes *continued...*

¹⁴ Congressional Budget Office, *Budget Options, Volume 1, Health Care*, Chapter 10, Long-Term Care, pp. 193-204. Available online at www.cbo.gov/doc.cfm?index=9925.

¹⁵ Holahan, et al., *Ibid*.

¹⁶ See pp. 34-37 of Senate Finance Committee's options paper on expanding health care coverage at: finance.senate.gov/sitepages/leg/LEG%202009/051109%20Health%20Care%20Description%20of%20Policy%20Options.pdf.

¹⁷ 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.

¹⁸ Weil, Alan, "A New Approach to the State-Federal Relationship in Health," *Health Affairs*, Vol. 28, No. 2, January 2009.

¹⁹ *Ibid*.

²⁰ "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 www.statehealthfacts.org/comparecat.jsp?cat=4.

²¹ 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.

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²⁴ "How Much of a Difference Will the Economic Stimulus Package Make to the States," stateline.org, February 17, 2009 at www.stateline.org/live/details/story?contentId+3777039.

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²⁶ 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 www.nasdds.org/pdf/HowToManageInAnEconomicDownturn.pdf.

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on Developmental Disabilities

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