CHAPTER VII

THE HCB WAIVER PROGRAM: PRESENT STATUS - FUTURE PROSPECTS

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The HCB waiver program, as it enters its tenth year, is playing a vital role in assisting the states to respond to the needs of a growing number of people with developmental disabilities. By the end of 1991, all but a handful of states are likely to be operating waiver programs on behalf of people with developmental disabilities.

Taking into account: (a) the growth in the number of states operating MR/DD waiver programs; (b) the authority states already have to expand their programs over the next three-to-five years; and, (c) ongoing efforts by the states to reduce the number of residents served in large public institutions, there is every prospect that the number of HCB waiver program participants will continue to increase steadily. A conservative projection might be that the number of program participants will reach 75,000 by 1995.

In this chapter, we take stock of the program's strengths and weaknesses. We also discuss various steps that might be taken to improve federal program policies. Finally, we examine the lessons learned from the HCB waiver experience and their potential application to crafting more satisfactory federal Medicaid policies affecting services for people with mental retardation and other developmental disabilities.

A. The HCB Waiver Program: An Assessment

The growing role of the HCB waiver program in meeting the needs of people with developmental disabilities since 1986 is the strongest evidence of its value. Despite the ebb and flow of the problems that states have encountered in making use of this unique Medicaid financing authority, they have continued to press ahead in expanding the number of program participants. The fact that growth in the number of ICF/MR recipients nationwide has been negligible since 1982 provides additional evidence that the HCB waiver program has come to be regarded as a superior means of employing Medicaid dollars to meet the needs of people with developmental disabilities.

The story of the HCB waiver program and its effects on community developmental disabilities services over the past five years has been the triumph of home and community-based services "alternatives" over the congregate care ICF/MR model. As we pointed out in 1989 (Smith and Gettings), the HCB waiver program has accounted for all but a very small percentage of the growth in the number of people with developmental disabilities who receive Medicaid financed long term care services since 1982. States have decided that the HCB waiver program is a superior way of accessing federal dollars to meet the needs of people with severe, life-long disabilities. There now are more participants in HCB waiver financed services than are served in small, community-based ICF/MRs, and the gap between the level of participation in the two programs can be expected to grow wider and wider over the next few years.

Over the past three-four years, there also is growing evidence that state MR/DD HCB waiver programs are beginning to finance an even wider range of services under their HCB waiver programs. It is increasingly common to find states employing the HCB waiver program as a means of fostering the development of supported living arrangements, creative responses to the needs of children with developmental disabilities and their families, programs aimed at senior citizens with developmental disabilities, and other home-based service options. State programs today provide for a wider range of service options than three-four years ago when they were dominated by more or less conventional adult daytime and residential service models. Steadily, "second generation" HCB waiver programs are emerging that feature an improved capability to tailor services and supports to the unique needs and circumstances of individual program participants.

This trend, of course, is reflective of the broad-based evolution of community developmental disabilities services. The current trend is toward deemphasizing the "continuum of care" as the central organizing principle of publicly-funded developmental disabilities services, in favor of promoting more individualized "supports" to assist individuals to live more independently (Bradley, and Knoll, 1990; Smith, 1990). The inherent flexibility of the HCB waiver program has permitted states to shift Medicaid financing of community services towards promoting these new approaches.

While the last chapter has not been written on the steadily expanding role of the HCB waiver program in assisting people with developmental disabilities to live and work in their own communities, the program is now sufficiently mature that states are moving beyond the initial program implementation stage toward the exploration of ways in which the HCB waiver program might become even more effective and responsive to meeting the needs of people with developmental disabilities. At this juncture, several important lessons have been learned as an outgrowth of states' experiences with the HCB waiver program:

> First, when the dollars available to support people with severe, lifelong disabilities in home and community-based settings are more or less equal to the dollars available for congregate care services, then barriers to independence and integration can be overcome. The ICF/MR program's "competitive advantage" has been shown to lie in the enhanced resources that have been available for such services rather than in any inherent advantage of congregate care services based on an "active treatment" programming model. Once this economic advantage is removed, the "need for institutionalization" becomes questionable.

The HCB waiver program has aided enormously in changing views regarding the extent to which an individual's disabilities should determine the appropriateness of placement in a congregate setting with its inherent restrictions on integration and independence as well as individual choice. Facility-based programs no longer seem to be quite the "necessity" that they once were.

> Second, nine years of experience with the HCB waiver program has demonstrated that providing broad flexibility in the types of services and supports that can be furnished to people with

developmental disabilities yields more cost effective outcomes. One a per capita basis, the costs of HCB waiver services are exhibiting substantial stability at levels far below the comparable costs of ICF/MR services within and outside the public sector. In contrast, the costs of ICF/MR services continue to spiral upward. There is now little doubt which model of programming and paying for services offers the best prospect of meeting the needs of people with developmental disabilities in the most cost effective fashion.

Third, the innovative services being developed by states through their HCB waiver programs offer strong testimony to the wisdom of structuring federal policy in a manner that grants states considerable latitude in shaping Medicaid-reimbursable developmental disabilities services. Creativity, like politics, is locally based. There seems little doubt that, had more proscriptive federal policies been enacted in conjunction with the HCB waiver program, fewer innovative approaches would have emerged.

Fourth, there is ample evidence that the general quality of services being furnished to HCB waiver program participants is excellent. Since 1987, a number of independent assessments have been conducted on HCB waiver programs serving persons with mental retardation and related disabilities. Typically, these assessment have found that states have lived up to their obligation to protect the health and safety of waiver participants. In many cases, these assessments have concluded that program participants are receiving highly effective services that have demonstrably beneficial outcomes. Both consumers and their families have voiced considerable satisfaction with the services being furnished through state HCB waiver programs.

In short, there is no evidence that HCB waiver programs provide lower quality services than the services received by people residing in ICF/MRs. Indeed, at this juncture, far more evidence exists of positive outcomes on behalf of HCB waiver participants with developmental disabilities than has been documented in ICF/MR settings.

Fifth, in sharp contrast to the conventional wisdom of only a few years ago, financing MR/DD community-based services through the HCB waiver program has proven to be no more risky for the states than any other Medicaid-reimbursable service. While a limited number of states have encountered problems stemming from federal audits and program reviews, on the whole the number of such adverse outcomes has been limited -- in both scope and quantity. In short, the HCB waiver program has proven to be a stable source of Medicaid financing.

Sixth, the reliability of the waiver authority as a funding source is an outgrowth of the fact that states -- by and large -- have had sufficient experience with the HCB waiver program to allow them to develop sound administrative policies and practices. The "technology" of managing HCB waiver programs today is relatively

> mature in most states. Concurrently, the HCB waiver program has permitted states -- and particularly state MR/DD agencies -- to acquire extensive expertise in managing Medicaid financed services in concert with their overall community-based developmental disabilities service delivery systems.

In short, the HCB waiver program has demonstrated the inherent soundness of the principles upon which it was based. Home and community-based services can serve as effective, satisfactory, and practical alternatives to institutionalization and such alternatives are no more (and, frequently, less) costly than institutional services. Flexibility in the types of services that can be furnished to program participants is a key ingredient in developing practical alternatives to institutional placements. Granting states wide-ranging flexibility in the design and management of these programs yields more effective outcomes than adopting proscriptive federal policies that foreshorten opportunities for locally conceived innovations.

In short, the HCB waiver program has succeeded in meeting its aims — indeed to a far greater extent than many observers believed possible only a few years ago. For the future, there is every prospect that this program will loom even larger in meeting the needs of people with developmental disabilities.

At the same time, it also is more and more evident that certain federal policies constitute serious barriers to evolving an HCB waiver authority which is capable of playing an even larger and more effective role in assisting people with developmental disabilities achieve improved levels of independence, productivity, and integration. Nearly ten years of experience with the HCB waiver program have highlighted not only its strengths but also many of the defects in the key federal policies which govern it.

These defects evidence themselves in a wide-variety of ways which, to one degree or another, pose critical barriers to its continued growth, responsiveness and effectiveness. In particular:

> First, the use of the so-called "cold bed" rule to regulate the scope of waiver services is the program's most serious defect. This administrative policy -- hatched during the Reagan Administration as an arbitrary device to control program growth -- is an enormous barrier to states' making broader use of the HCB waiver program to meet the needs of people with developmental disabilities. Certainly, there is no other federal HCB waiver policy that evokes quite so much frustration on the part of state officials.
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> The cold bed rule ties growth in utilization of waiver services to: (a) each state's willingness to demonstrate or resolve to expand ICF/MR services, despite the fact that most states now regard the ICF/MR program as problematic, too expensive, and increasingly inappropriate; and (b) its previous utilization of ICF/MR services. The cold bed rule disadvantages states that adopted more balanced approaches to service system development. Furthermore, it disadvantages all states interested in promoting a

wider range of home and community-based services for people with developmental disabilities.

While HCFA's enforcement of the cold bed rule (which continues to be watched over by the President's Office of Management and Budget) has been less stringent in recent years than previously, the fact remains that the rule continues to depress program growth. The cold bed rule has no basis in federal statute, yet continues to define – however artificially – the programs limitations. The rule is held in place by a federal budgetary environment that results in any attempt to overturn it being painted as an addition to federal outlays. As states increasingly turn away from the ICF/MR program, the effects of the cold bed rule will worsen.

Second, despite the fact that HCB waiver services furnished to people with developmental disabilities are to serve as alternatives to ICF/MR services, there is little doubt that the ICF/MR program's service delivery principles continue to exercise an inordinate influence on the HCB waiver program. Continuously lurking in the background of the HCB waiver program is the notion that the range and scope of the services furnished to program participants somehow must comport to the "active treatment" model of the ICF/MR program. HCFA's largely unwritten policies in this regard continue to foster the expectation that services furnished as part of HCB waiver programs should yield the "moral equivalent of active treatment."

Again, there is no basis in federal law for such implicit policies. At the same time, states are cautious in departing too far from the standards of active treatment. Indeed, in many state HCB waiver programs, the objective of furnishing active treatment services in affirmed.

At a very fundamental level, this continued use of the ICF/MR program model as the benchmark for HCB waiver programs works at cross-purposes with: (a) achieving person-centered approaches to meeting the needs of people with developmental disabilities; (b) assuring the continued cost-effectiveness of HCB waiver programs; and, (c) promoting independence and integration on behalf of program participants.

At issue is whether the services that states furnish under their HCB waiver programs will reflect the "community membership" paradigm that stresses a more balanced, person-centered approach to furnishing services and supports to people with developmental disabilities and their families (Bradley and Knoll, 1990) or whether waiver programs must adhere to the increasingly suspect "developmental model" with its overemphasis on clinically-derived service delivery aims.

Third, the essential conflicts between certain premises of the federal Medicaid program and state developmental disabilities service delivery systems continue to arise. State developmental disabilities service delivery systems have evolved more or less along the decentralized lines that delegate key decisions to local agencies. Indeed, there is a growing recognition of the need to keep program management as localized as possible within the overall context of broad state policy goals and objectives.

Federal Medicaid policies are based on the presumption of unitary service delivery models that are managed in a standardized fashion by a central authority — the state Medicaid agency. These policies are more or less anchored in an acute care health insurance model rather than in the alternative model of decentralized decisionmaking.

Over the past three-four years, these fundamental conflicts have bubbled to the surface in the guise of such issues as factoring, freedom of choice, and provider contracting policies. States have been forced to change HCB waiver policies to comport with federal Medicaid policies that draw their justification from a centralized, single purchaser model of managing health care services. In some cases, these conflicts have been so intractable that they have stymied state efforts to expand their programs (the extreme example being California's inability to secure approval of a renewal waiver request for a period that exceeds two years at this writing).

These essential policy conflicts are all the more frustrating because there is no evidence that the policies that states have been forced to change were inappropriate or that compliance with federal policies resulted in better program administration or more effective services. Even HCFA officials have admitted that the models employed in some states that have run afoul of these federal policies probably represent more effective approaches to managing service delivery.

From a broader perspective, these conflicts stem are the product of Congress[1] decision to graft the home and community-based waiver authority onto the Medicaid program without examining the need to make changes in fundamental Medicaid policies to accommodate such non-institutional service options.

Fourth, the administrative overhead associated with the HCB waiver program appears to be particularly onerous, particularly in comparison to other state-funded community developmental disabilities programs. With the growing use of Medicaid dollars to meet the needs of people with developmental disabilities has come an administrative structure that it is costly to maintain and operate. These burdens -- characteristic of all Medicaid-reimbursable services — are particularly taxing and draw attention away from more basic concerns regarding the quality and effectiveness of the services furnished to program participants. With due acknowledgment for the need for accountability in public programs, the administrative requirements of the HCB waiver program are detracting from the cost effective delivery of services.

In one way or another, the preceding problems detract from the capability of the HCB waiver program to play an even more decisive role in assisting states to realign their service delivery systems along more person-centered, responsive and cost-effective lines.

B. Near-Term Changes in the HCB Waiver Program

During 1990, it became clear that the prospects for achieving broad-scale reforms in federal Medicaid policies affecting services to people with developmental disabilities are remote. Despite more than seven years of debate concerning Senator Chafee's Medicaid reform proposals, disagreements about basic issues, coupled with the intractable federal budget deficit, makes it unlikely that Congress will approve basic statutory reforms during the next several years.

For better or worse, the most likely path toward improving federal policies lies in correcting problems with current programs and making them more useful in meeting the needs of people with developmental disabilities. With regard to the HCB waiver program, several changes – some long overdue -- would go a long way toward improving the effectiveness of this financing option. Among the changes that should be given serious consideration are the following:

1. Cold Bed Rule

Obviously, the most significant step that could be taken to improve the utility of the HCB waiver program is to replace the cold bed rule with a more constructive, even-handed means of assuring the cost-effectiveness of waiver services. Barring more broad-based reform and given the reality of the federal budget deficit, the HCB waiver program will continue to be subject to caps on the number of program participants and expenditures. The issue is not that such caps will persist but rather finding a fairer and more constructive approach to the way in which they are determined.

In this light, HCFA's proposal to permit states to convert their HCB waiver programs to state plan status but subject to stringent limits on future growth has little merit. Under HCFA's proposal, the present, unequal distribution of HCB wavier "slots" among the states would persist, with a state's only recourse to argue for added slots by reference to the cold bed rule. Moreover, HCFA's proposal simply fails to recognize the ongoing role of the waiver program in deinstitutionalization or its potential role in meeting the needs of nursing facility residents with developmental disabilities who could benefit from community placements. Indeed, the long-term consequences of HCFA's proposal would be to place stringent controls on the HCB waiver program while allowing the ICF/MR program to grow unchecked despite the proven cost-effectiveness of HCB waiver services.

The solution to the problems posed by the cold bed rule does not lie in substituting a more stringent option. Instead, a fair approach that recognizes that the HCB waiver program will continue to be subject to utilization and spending caps would have the following features:

> First, any state which has an approved waiver program should be permitted to convert its program to state plan status, subject to a cap on growth in annual spending equal to the rate of inflation plus at least a 5 percent annual increase in the number of program participants.
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> Second, there should be no cap on the number of program participants. If, within the overall cap on spending, a state is able to serve more individuals, so much the better, subject only to the basic test that per capita expenditures continue to be less than or equal to per capita ICF/MR expenditures.
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> Third, a state's expenditure cap should be automatically adjusted to reward a state for reduced ICF/MR utilization and/or placement of individuals from nursing home into home and community-based services.
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> Fourth, states operating under caps significantly below the nationwide average should be permitted to catch up (over a three-five year period).

The preceding approach would be far more attractive to most states than HCFA's proposal. The fiscal consequences of this proposal also would be modest in all probability. Such an approach, however, would permit states to plan for program expansions in a more orderly fashion. In addition, by removing caps on the number of program participants, undoubtedly the cost effectiveness of waiver programs would improve still further.

2. Supported Employment

The current restriction on the availability of prevocational and supported employment services to persons who were previously institutionalized makes no sense and should be eliminated. All waiver participants -- including those who have never resided in a Medicaid-certified institution but, nonetheless, meet ICF/MR level of care criteria -- should be permitted to receive such services. In February, 1990, HCFA issued proposed rules which, in effect, would make it clear that ICF/MR residents can receive Medicaid-reimbursable prevocational, vocational, and supported employment services, provided that such services are necessary to furnish the subject individual with active treatment service. To continue to deny the availability of these services to some HCB waiver program participants is discriminatory and defeats the fundamental aims of the program.

Viewed from a broader perspective, federal HCB waiver statutes should be amended to incorporate forward-thinking definitions of prevocational and supported employment services that give full recognition to the value of furnishing program participants with services and supports that will lead to gainful, permanent employment. Such an outcome not only makes programmatic sense but fiscal sense as well.

3. OBRA-87 Waiver Programs

The HCB waiver statute should be amended to provide states with further latitude in furnishing HCB waiver services to individuals who have been denied admission to a nursing home under the pre-admission screening provisions of OBRA-87. In 1990, NASMRPD offered a modest proposal along these lines -- one which would permit a state to replace an OBRA waiver program participant who leaves the waiver program with another individual who had been denied admission to a nursing facility. This proposal deserves favorable consideration since it would improve the states' capacity to use HCB waiver services to meet the needs of people with developmental disabilities who are proposed for admission to nursing facilities. Such a revision in current law would be "budget neutral" and also would offer providers of OBRA waiver services greater assurance of a more or less constant caseload, acting as an inducement to participation.

4. Factoring, Freedom of Choice, and Contracting

Federal policies need to be changed so that technical violations of Medicaid requirements does not trigger basic changes in key state policies governing the organization and delivery of community developmental disabilities services. Over the past two years, states have encountered more and more problems in securing approval of initial or renewal HCB waiver requests due to conflicts between state statutes governing the organization and delivery of community MR/DD services and federal Medicaid provisions related to freedom of choice, provider agreements, and "factoring" of Medicaid payments. Typically, these conflicts arise when a state's statutes require local substate agencies (public or private non-profit) to act as the legally responsible local body administering state-funded services to people with developmental disabilities. Conflicts also arise when state statutes delegate to a single entity within a given geo-graphic catchment area responsibility for the delivery of case management services to individuals with developmental disabilities.

The conflicts stemming from these and potentially other "generic" federal Medicaid provisions: (a) make it difficult to organize the delivery of services in ways that do not involve a direct contractual relationship between the single state Medicaid agency and the provider of each HCB waiver services; and, (b) prevent a state for limiting the provision of HCB waiver services to providers recognized under state law or regulation.

While most states have found ways of accommodating these federal requirements without completely dismantling or rearranging their community service delivery systems, not all have been able to. Where states have complied with federal requirements in spite of state statutes that do not quite square with such requirements, generally the result has been a gerry-rigged system that complicates program administration, without any offsetting improvements in the quality or appropriateness of the services being delivered.

In our view, two changes in federal law would resolve the bulk of the problems that have ben encountered thus far:

> First, states should be given the same authority to limit the providers of case management services under the HCB waiver program as they currently have under the provisions of Section 1915(g) of the Social Security Act, which authorizes the coverage of "targeted case management" services. Armed with this authority, states could avoid the most serious problems that have emerged concerning recipients' freedom of choice under the HCB waiver program.
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> Second, Congress should affirm that state statutes granting local governmental or private, non-profit agencies the authority to contract on behalf of a state with HCB service vendors for community-based developmental disabilities services shall not be found to conflict with Sections 1902(a)(27) or 1902(a)(32) of the Social Security Act so long as a state assures the Secretary of HHS that such arrangements will not: (a) violate essential HCB waiver program requirements; or, (b) affect payments made to HCB waiver service providers. Such a provision would resolve most issues that have arisen with respect to factoring and contractual requirements under the HCB waiver program.

In both cases, the changes recommended above would simply acknowledge that state statutory provisions governing the delivery of community developmental disabilities services should be respected so long as essential federal policy aims are not adversely affected. Again, it is important to point out that, where states have encountered problems in this area of policy, the issues that have arisen have concerned technical compliance rather than breaches of fundamental statutory objectives.

5. Program Administration

States should be given the latitude to manage their HCB waiver programs in the most organizationally efficient manner possible. In most states, the state's MR/DD authority plays a significant, ongoing role in the management of HCB waiver services on behalf of people with developmental disabilities. However, frequently the state MR/DD agency shares responsibilities for program administration with the state Medicaid agency, which can lead to administrative inefficiency.

> Given the present role played by most state MR/DD agencies in administering HCB waiver programs, it would make sense to grant the Governor of each state the authority to designate the state MR/DD agency as the responsible administering agency for the HCB waiver program, provided that this delegation of authority clearly reaffirms the state's intent to comply with all waiver assurances. This statutory change would permit states -- at their option -- to simplify program administration.

The changes described above would go a long way toward placing the HCB waiver program on a firmer footing. The substitution of new program limitations for the cold bed rule is a change that is long overdue. The other suggested changes would eliminate many of the problems that have arisen in recent years or simply make the HCB waiver program a more flexible tool for meeting the needs of people with severe, life-long disabilities.

C. Toward New Federal Policies

For the past decade, it has been evident that federal Medicaid policies affecting services to people with developmental disabilities are sorely in need of basic reform. These policies remain, in one way or another, anchored in the philosophy that governs the ICF/MR program, a program that in 1991 will mark its 20th anniversary. The contemporary vision of services to people with developmental disabilities -- promoting independence and productivity in truly integrated service settings -- and the premises of the ICF/MR program (the treatment of deficits in specialized facilities) have become increasingly divergent as the years have passed.

This conflict in underlying philosophies has become increasingly evident as the HCB waiver program has evolved. The waiver program can support a wide range of services and supports to people with developmental disabilities and their families. At the same time, the "need for institutionalization" remains a basic eligibility criterion for waiver services and is still too influenced by the precepts of "active treatment".

To address this limitation in current law, federal policies must be altered to affirm the value of supporting people with developmental disabilities through the provision of wide-ranging services and supports aimed at promoting independence, productivity, and integration. To continue on the current course would be a substantial disservice to such individuals and their families while also detracting from the capability of states to redirect their community service delivery systems to assure better use of scarce public dollars.

The HCB waiver program has demonstrated both the validity of meeting the needs of people with developmental disabilities in settings which are far less restrictive than those required under ICF/MR rules as well as the cost-effectiveness of making available a wide-range of services and supports to such individuals. The critical questions today do not involve finding new methods or models of service delivery that can be superimposed on existing federal policies but rather how to build upon the "lessons learned" through the HCB waiver program in designing a more satisfactory set of federal Medicaid policies affecting services to persons with developmental disabilities.

In 1990, Congress enacted a new, limited state Medicaid plan authority, entitled "community supported living arrangements" (CSLA) services. This authority is noteworthy because it does not tie eligibility for services to the "need for institutionalization" test; nor does it condition federal Medicaid payments on the delivery of "active treatment" services. The CSLA authority builds constructively on the experiences of states in furnishing supported living and home-based supports to people with developmental disabilities under their HCB waiver programs. Moreover, this new authority embodies -- at least potentially -- a more mature federal-state relationship in assuring the quality of services to people with developmental disabilities.

While the CSLA authority is far too limited to be hailed as "Medicaid reform", it nonetheless points the way toward a new paradigm under which more extensive changes federal policies can be contemplated.

The initial steps toward the adoption of more satisfactory policies affecting services to people with developmental disabilities must begin from the premise that the provision of such services should not depend on the "need for institutionalization" test. Contemporary developmental disabilities service delivery values and precepts reject the notion that such a "need" exists and can be measured. Moreover, reforms must be based not on restricting federal dollars to supporting treatment aims (justified by "comprehensive functional assessments" performed by clinicians) but on providing wide-ranging services and supports needed to promote independence, productivity and integration. In other words, the essential aims of federal Medicaid policies must be revised so that the purpose of federal assistance is not to "fix disabilities" but to promote community presence and participation.

Obviously, revamping federal policies along these lines will require answers to a variety of extraordinary difficult questions that have yet to be addressed satisfactorily during the debate surrounding developmental disabilities Medicaid reform legislation over the past seven years. In particular:

> Clearly the principal barrier to achieving basic reforms in Medicaid policies lies in the potential budgetary implications of any changes that would have the effect of expanding eligibility to a significantly wider target population and increasing the range of services and supports that may be financed through the federal-state Medicaid program. Today, roughly 210,000 Americans with developmental disabilities receive HCB waiver or ICF/MR services. However, more than 1.3 million people with developmental disabilities are eligible for Medicaid and presumably could benefit from one type of long term care service or another.
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> Present federal policies governing the HCB waiver program have more or less contained federal outlays for community services. If, in the face of the burgeoning federal budget

deficit, basic reforms are prevented due to their budgetary consequences, the present gridlock will continue, to the detriment of all parties.

This suggests that serious consideration must be given to alternative approaches that realistically acknowledge both federal and state budget problems. In other words, if a full-blown entitlement to services and supports for people with developmental disabilities is unattainable in the near to mid-term, is there another avenue that will: (a) keep federal outlays within acceptable limits; and (b) avoid simply mandating that states sharply increase their spending?

One potential approach may be to establish what might be termed a capped entitlement that fundamentally alters basic federal policies by permitting both the states and the federal government to limit their outlays over an extended period of time. While such an approach obviously would fall far short of establishing a method of financing a broadly accessible range of services and supports to all people with developmental disabilities who are eligible for Medicaid, it might be far preferable in today's policy gridlock or other options that might limit eligibility based on degree of impairment.

Any "Medicaid reform" proposal must confront nagging questions about the ICF/MR program. Over the past five years, spending for ICF/MR services has soared even though the number of people receiving such services has remained almost constant. Increased outlays are not resulting in better capacity to meet the needs of all persons with developmental disabilities, but instead are skewing public dollars toward a limited subset of the MR/DD population. Runaway ICF/MR costs, for example, are having a deleterious affect on the capacity of states to meet the needs of people who have been consigned to waiting lists. Unless current federal policies are changed, these trends will simply continue and exacerbate the present imbalance between dollars spent on ICF/MR services and other types of community services.

At the same time, after seven years of debate about Medicaid reform proposals would arbitrarily cut payments for ICF/MR services, it is also clear that such proposals are very unlikely to be adopted by Congress because they are strongly opposed by a host of special interest groups. Yet, unless some fundamental changes occur, it will be exceedingly difficult to achieve broad-scaled Medicaid reform.

Expansion of Medicaid-reimbursable community services must be accompanied by: (a) reconsideration of present federal ICF/MR policies; (b) giving the states more effective tools to manage ICF/MR utilization; and, (c) innovative steps that can permit states and ICF/MR providers to work together constructively to promote the conversion of current programs to more satisfactory alternatives.

For example, states need to be aimed with more explicit authority to cap the use of ICF/MR services. In addition, federal participation in the costs of converting existing ICF/MRs to more satisfactory, community programs would be a wise, long-term investment, both in programmatic and in fiscal terms.

Another substantial barrier to basic reforms is the difficulty in striking an acceptable balance between the roles of federal and state government in managing and overseeing long term care services to people with developmental disabilities. It seems clear that assigning primary responsibility for overseeing such services to the federal government is objectionable to states and, more importantly, is out-of-place in a service delivery environment where the emphasis increasingly is on person and community-centered service strategies. Locking service requirements and quality assurance mechanisms into federal law is likely to lead to a repetition of the ICF/MR experience: an over emphasis on "health and safety" that leads to a rapid increase in costs and substantial impediments to program innovation at the point of service delivery.

In this light, the framework provided in the recently adopted CSLA authority merits strong consideration. Ultimately, federal policies in this regard must be premised on effective state management of community MR/DD services within the broader context of the outcomes sought by federal laws and administrative policies.

Finally, the current administrative apparatus of the Medicaid program is inefficient and overly costly. If the aim of Medicaid reform is to extend services and supports to more people with developmental disabilities in as economically a manner as possible, then the high costs of administering Medicaid programs needs to be part of the reform equation. Reform should build on current state systems and not be based on the creation of additional layers of program administration or additional requirements that simply raise the costs of services.

In the present climate, achieving broad-based reform of federal Medicaid policies affecting services to people with developmental disabilities may not be possible. At the same time, the HCB waiver experience strongly suggests that reform need not be synonymous with starting over from scratch. Valuable lessons have been learned as a result of this experience. Certainly, these lessons need to be duly acknowledged in efforts to revamp current federal policies to achieve better outcomes on behalf of people with developmental disabilities.