LONG TERM SERVICES AND SUPPORTS FOR PEOPLE WITH MENTAL RETARDATION:

Reflections on Current and Future National Policies

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> *In every picture of the future there is a dim spot which the eye of understanding cannot penetrate.*
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> Alexis de Tocqueville
> Democracy in America

Over the past twenty five years, the federal government has played an extraordinarily important role in creating new opportunities for people with mental and physical disabilities. Even an abbreviated list of the national legislative milestones that were achieved during this remarkable period underscores the far reaching impacts which federal policy have had on bringing people with disabilities into the mainstream of American society:

> The Rehabilitation Act of 1973, which prohibited discrimination on the basis of disability in all federal and federally-assisted programs;
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> The Social Security Amendments of 1972, which established the Supplemental Security Income (SSI) program, through which an estimated 1.3 million children and adults with mental retardation and other developmental disabilities now receive basic monthly subsistence payments;
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> The Education of All Handicapped Children's Act of 1975, which established in federal law the principle that every child, regardless of the nature or severity of his or her disabilities, has a right to a free and appropriate public education;
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> The Education of the Handicapped Act Amendments of 1986, which extended the "zero reject" principle from public education to early intervention services for infants and toddlers with disabilities; and, of course

> The Americans with Disabilities Act of 1990, which established explicit federal statutory protections against discrimination in employment, transportation, public accommodations and public services of all sorts, as well as in the use of telecommunication systems.

Although the impact of these and other disability-specific statutes has been a recurring topic of discussion among advocates and professionals in the field for the past two decades, far less attention has been given to the quiet revolution that has been taking place in the organization and delivery of long term services and supports for people with lifelong disabilities, and, more specifically, the role the federal government has played in this process. Perhaps because the impetus for these changes has come largely from the state and local level, rather than as the result of the passage of landmark federal legislation, many usually well-informed members of the disability community have yet to grasp the full significance of the changes that are underway or the related implications for future federal policy in this area.

The purpose of this paper is to briefly review recent developments in federal long term care policy as it impacts on the provision of services and supports to people with mental retardation and other developmental disabilities. The paper also summarizes several of the major public policy challenges that lie ahead.

The Pervasive Impact of Medicaid Funding

Over the past two decades, the financing of long term services and supports for people with developmental disabilities has become almost totally dependent on federal-state Medicaid payments. In FY 1977, about one quarter of the $3.5 billion the states expended on specialized MR/DD services was derived from Medicaid reimbursements (Braddock.et. al., 1990). Last fiscal year (FY 1993), the states, collectively, spent more than $15 billion on such services (or more than four times the total seventeen years earlier); of this total, over $13 billion, or more than 85 percent of the total, was obtained through federal-state Medicaid payments (NASDDDS, 1992). It is rare indeed these days for a state MR/DD agency to consider a significant new or expanded program initiative without first formulating a strategy for assuring federal financial participation through the Medicaid program. As a result, anyone interested in understanding the dynamics of current and future federal long term policy as it impacts on people with developmental disabilities must begin by studying the factors which have contributed to the service system's present heavy reliance on Medicaid financing.

Some of the reasons that states increasingly have turned to Medicaid as a funding source for developmental disabilities services are rather self-evident. They include:

> *the extraordinarily high rate of Medicaid eligibility among people with developmental disabilities.* Except under very unusual circumstances, states are required by federal law to extend Medicaid eligibility to recipients of federally-assisted cash benefits (i.e., AFDC or SSI beneficiaries). Most

adults with developmental disabilities typically have little income or resources of their own and, according to federal law, the income/resources of their parents cannot be taken into account in determining whether they are eligible for SSI or Medicaid benefits. In addition, an individual with disabilities of sufficient severity to require ongoing services and support during adulthood unusually will meet the SSI/OASDI definition of disability. A high percentage of adults with developmental disabilities, therefore, will qualify for SSI benefits and with it automatic Medicaid eligibility, even in states with restrictive Medicaid eligibility policies. In the case of individuals who fail to meet the SSI income/resource test (often because they are the recipients of OASDI benefits), they may be qualified, nonetheless, for Medicaid-reimbursable long term services through a state's medically needy or spend down criteria or, more commonly, through the establishment by the state of a higher protected income standard.

In the case of a child under 18 years of age, the income and resources of the parents are taken into account in determining whether the child is eligible for Medicaid benefits. As a result, a much lower percentage of children with developmental disablities can be expected to qualify for Medicaid-funded long term services and supports. But, recent changes in federal law have increased substantially the number of children who potentially may receive Medicaid-reimbursable services. The actions taken by Congress between 1986 and 1990 to decouple the Medicaid eligiblity of pregnant women, infants and children has raised the percentage of poor youngsters who are entitled to receive Title XIX-funded services by more than 50 percent (from 48% in 1987 to 74% in 1991); furthermore, by FY 2002 states are required under current law to extent Title XIX coverage to all children living in families with income under the federal poverty level.

In addition, a number of other changes have been made in Medicaid law which have broadened the potential ways in which a state may assist children with special health care needs through their Title XIX programs, including: (a) clarification of the responsibility of the Medicaid program to pay for medically necessary "related" services on behalf of Title XIX-eligible children who are enrolled in early intervention, preschool and special education programs; (b) the enactment of much stronger requirements governing the screening and treatment of Medicaid-eligible children with chronic illness and disabilities under the so-called EPSDT provisions of Title XIX; and (c) the addition of a special eligibility category which gives states, under certain circumstances, the option of extending Medicaid-reimbursable home care benefits to children with severe disabilities who are at high-risk of institutionalization but otherwise would not qualify for Title XIX-funded services on the basis of the family's income and resources.

Because of the unpredictable fiscal consequences of the latter provisions, many states have been slow to take full advantage of them. However, the potential that they hold can be seen by examining the experiences of some of the states that have begun to recognize the fiscal as well as the programmatic advantages of linking Medicaid funding to an aggressive, proactive statewide strategy of early intervention and family preservation (e.g., FL, LA, MI, MN, NH and WI).

the existence of a rich pool of potential state/local matching dollars. The need to substantially improve the deplorable conditions which often existed in state-operated residential facilities prior to 1970 was the initial rationale for authorizing Medicaid funding of specialized intermediate care facilities for persons with mental retardation and related conditions (ICF/MR). Not surprisingly, most state were quick to take advantage of this new coverage option, since, in effect, it offered them a ready mechanism to finance desperately needed improvements in the physical plants and staffing levels of publicly-operated mental retardation facilities largely through the additional Medicaid payments they were entitled to receive from the federal government. The *quid pro quo* of the ICF/MR coverage option was that participating states were required to bring all Medicaid-certified facilities into compliance with federal standards by a date certain or federal financial participation would be terminated.

During the early years of the ICF/MR program (i.e., the mid-70s to the early-80s), the primary focus of state activity was on bringing public MR institutions into compliance with federal operating standards. The average annual per capita cost of operating such facilities nationally nearly quadupled during this period (Lakin, et. al., 1989). In response to the growing consensus among advocates and professionals -- spurred on in many cases by major class action law suits - that people with developmental disabilities typically benefit from living in the community rather than in segregated institutional settings, by the early 1980s most states had begun to emphasize the initiation and expansion of community-based services. Some states moved more rapidly than others to link their deinstitutionalization/communization initiatives to Medicaid financing, but by the end of the decade Medicaid had become the principal vehicle through which all states financed improvements and expansions in community-based MR/DD services.

Early efforts to qualify community services for Medicaid financing were focused to a large extent on certifying group homes as providers of ICF/MR services, although a few states also demonstrated that it was possible to support various elements of day and residential services for people with developmental disabilities through such Title XIX state plan options as clinic services, personal care and rehabilitative services. For the majority of states, however, the home and community-based waiver authority, which was added to Medicaid law in 1981, became the first broad-based vehicle for financing community developmental disabilities services through Title XIX.

Regardless of the timing or the circumstances of a state's decision to rely on Medicaid funding as a major source of support for community MR/DD services, one critical element was almost always present: the state had available or could generate relatively easily the state/local dollars necessary to draw down federal Title XIX payments. The capability of leveraging available state/local resources in ways that would strenghen and diversify community service delivery systems was the single most important reason why states became so heavily dependent on Medicaid funding of developmental disabilities services. Why support a service with 100 percent general revenue dollars if the state could bill the federal government 50 to 80 percent of the cost through its Medicaid program -- especially when in many cases the state/local revenues that were displaced in the process could be used to fuel further expansions and improvements in community MR/DD services?

In the absence of the availability of an accessible pool of state/local matching funds, initially in the form of state institutional appropriations and later a mix of state facility and community service dollars, Medicaid certainly would be playing a much less prominent role in the financing of developmental disabilities services than it does today. In fact, the existence of such matching dollars is undoubtedly one of the major reasons why, proportionally, the Medicaid home and community-based waiver authority has been used far more extensively on behalf of people with developmental disabilities than on behalf of any other potential target population (including low income frail elderly individuals and non-elderly people with physical disabilities).

the fact that federal Medicaid funds are not subject to annual appropnation limits. As with all other open-ended federal entitlement programs, estimated Medicaid expenditures are built into the annual federal budget, in this case based largely on utilization and cost projections furnished by the states; but, since actual outlays are determined by the number of program recipients and the reimbursable services a state determines such recipients are eligible to receive during the course of a fiscal year (plus various idiosyncratic features of state billing practices), it is not unusual for the federal government and the states to end up spending more for Medicaid services - sometimes billion of dollars more -- than was originally projected. An unanticipated down turn in the economy, for example, can add several million people to the Medicaid rolls, nationwide. The collective

> impact of individual state decisions regarding provider rate increases, the election of optional service coverages, the expansion of hospital, nursing home and/or ICF/MR bed capacity, as well as decisions governing the submittal of HCB and other waiver requests are just a few of the other factors that can influence the accurary of federal Medicaid expenditure projections.
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> The insulating effect of this basic feature of Medicaid policy is difficult to over-estimate. Between FY 1987 and FY 1993, overall federal-state Medicaid spending more than doubled, increasing from $47.0 billion to $125.7 billion (or at an average compounded rate of 17.8 percent per year). The long term care component of Medicaid outlays grew at a somewhat slower pace than overall federal-state spending, but still nearly doubled over this same period (increasing from $21.1 billion to $41.9 billion) (Burwell, 1994). Given the recurring efforts by Congress and the White House to reign in the deficit over the past five years, it seems doubtful that this rate of growth in Medicaid outlays could have been sustained had annual program funding levels been subject to the scrutiny of the annual appropriation process. This is the reason why for years fiscal conservatives inside and outside of Congress have been calling for the imposition of a cap on Medicaid expenditures as well as expenditures under other major social entitlement programs (Medicare, SSI and, under some proposals, Social Security benefits).
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> Medicaid reimbursements for long term services to people with developmental disabilities, of course, are not the only -- or even the most significant -- factor in the recent rapid growth in federal-state Medicaid outlays. However, given the fact that federal Medicaid spending on developmental services roughly doubled over this same six year period (from about $3.5 billion to $7.5 billion), it is difficult to argue that MR/DD services are not at least one among many reasons for this continuing pattern of sharp increase in Title XIX outlays.

One often overlooked reason that the states have turned to Medicaid as a primary funding source for MR/DD services is the flexibility it affords the states. In a program as complex as Medicaid, with so many, often seemingly arcane statutory and regulatory ground rules, it may seem peculiar to refer to the program as a flexible funding vehicle; but it is important to keep in mind that, unlike the Medicare program, Medicaid is a federal-state program in which states are given a considerable degree of latitude in determining the scope of eligibility, the range of services to be offered, the way in which such services should be organized and delivered, and the amount that should paid for a given type and increment of service.

Since the advent of the home and community-based waiver program, the states have been afforded even greater latitude in shaping Medicaid-funded long term care services.

In essense, the HCB waiver authority gives the states a readily adaptable mechanism for: (a) targeting a tailored array of Title XIX-reimbursable services and supports to selected subpopulations of people with chronic disabilities, while circumventing the fiscal uncertainities associated with Medicaid's comparability test (which obligates a state to offer any service covered under its state plan to all similarly situated Medicaid recipients who need it); (b) receive federal financial participation in the cost of certain elements of home and community-based services which otherwise would not qualify for Medicaid reimbursement; and (c) organizing the delivery and financing of Medicaid-funded community services in a manner that is fully consistent with the state's overall program goals. The first advantage of the waiver is particularly critical since, faced with the "all-or-nothing" choice of adding allowable elements of community service coverage under their state Medicaid plans, historically states have either decided not to do so or circumscribed the conditions of coverage in such a manner that many potential users were unable to receive the types and intensities of assistance they required. By empowering the Secretary to grant exceptions to the comparability test (i.e., waivers), the HCB waiver authority gives states a method of pinpointing services to a predetermined number of recipients who meet a particular need profile without worrying about the potential "woodwork effect" of such action.

The states' experience in initiating community-based services for people with developmental disabilities under the HCB waiver authority offers an useful illustration of the malleability of Medicaid policy in this area. Until the late 1980s, most specialized HCB waiver programs for people with developmental disabilities were designed by the states to support a rather traditional array of community-based services -- habilitation and training services in group homes, facility-based day habilitation services, case management, respite care, etc. Over the last five or six years, however, at least half the states have requested and received approval from the Health Care Financing Administration (HCFA) to significantly broaden and diversify the range and types of services and supports offered through their HCB waiver programs. This development closely parallel the groundswell of commitment in the field of developmental disabilities to what has been referred to as the "community membership" or "supports" paradigm. This new approach to assisting people with lifelong disabilities stresses the importance of promoting self-sufficiency, personal choice, independence and the opportunity for people with disabilities to become fully participating member of their local communities. The fact that so many states have been able to instill these radically new concepts into their waiver program is a testament to both the latitude afforded the states under current Medicaid law as well as the foresightness of responsible HCFA officials.

It should not escape our attention, however, that compared to most of the major disability-specific laws that have been added to the federal statute books over the past twenty years, Medicaid has very few ideological underpinnings. Yet, ironically, the Medicaid program has emerged as the single largest source of federal financial assistance services to non-elderly people with disabilities.

Reflecting on the events of the past decade, one has to wonder whether the transition to this "new way of thinking" about disability policy would have proceeded more or less rapidly had the groundswell of advocacy in the mid-to-late 1980s for enacting separate statutory policies governing Medicaid-funded services to non-elderly people with disabilities achieved its objective. Perhaps, the lesson we need to draw from this experience is that the task of formulating future national long term care policy needs be approached with an abiding sense of humility about our collective capacity to anticipate future events. In the words of de Tocqueville, we need to be conscious of that "dim spot which the eye of understanding cannot penetrate."

The Clinton Long Term Care Reform Proposals

As this paper was being prepared, Congress was in the early stages of responding to President Clinton's call for fundamental changes in the American health care system. The highly ambivalent initial responses to the Clinton health reform plan among legislators and the general public strongly suggest that any legislation Congress ultimately approves probably would deviate significantly from the President's recommendations. The outlook for the long term care provisions of the Clinton plan, in particular, appeared to be particularly clouded. Unable to reach a consensus on critical aspects of reforming the delivery of basic health services, most legislators seemed ill-inclined to commit themselves to including major long term care provisions in national health reform legislation.

Still, seasoned Capitol Hill veterans know that the prospects for enacting any given set of legislative proposals can change, literally overnight, as Congress proceeds with the health reform debate. During the early stages of the legislative process, seemingly irreconcilable differences over basic issues is not an uncommon occurrence, especially when Congress is asked to tackle complex, controversial public policy questions. As consensus is achieved on the basic components of a legislative plan, however, often compromise approaches can be found for dealing with a wide variety of other issues and more comprehensive solutions emerge than appeared possible even a few days or weeks earlier. It is useful to remind ourselves that in 1986, at a similar stage of the legislative process, the odds of enacting major changes in federal tax laws appeared dim; yet, before the end of the year, Congress had approved the first comprehensive re-write of the U.S. tax code in over 30 years.

The centerpiece of the Clinton approach to restructuring long term care services is a proposal to create a new, capped, federal-state grant program to finance home and community-based services for people with severe, chronic disabilities, regardless of age, income and resources, or the nature and origin of an eligible individual's disabling condition. This new funding authority is designed to cover services and supports which participants would not be eligible to receive under other programs, including through the nationally guaranteed health benefit package, Medicare, or private insurance.

While the merits of the Administration's long term care proposals can be debated, by any reasonable measure, they represent a serious attempt to deal with a major societal program. Of at least equal importance, the Administration gives substance to the belief that no strategy for reforming the financing and delivery of health services in this country can be complete without addressing the unmet need for long term services and supports among millions of Americans with severe, chronic disabilities.

In addition, viewed from the perspective of the disability community, the President's proposed long term care reform strategy has several meritorious features, including its: (a) emphasis on home and community-based service alternatives; (b) attention to assuring that consumers and their families have a strong voice in determining their own support needs and how they should be met, as well as a major role in shaping related public policies; (c) recognition that the federal government must assume a pro-active leadership role in expanding and improving LTC services; and (d) strong commitment to giving states the latitude necessary to adapt their service delivery strategies to local conditions, within a broad federal policy framework.

Despite these positive aspects of the President's plan and regardless of whether Congress eventually includes key elements of the Clinton long term care proposals (or, at least, variations on the same basic themes) in a final health reform bill, individuals concerned about the future welfare of people with developmental disabilities need to give serious consideration to the fundamental tenets underlying the approach recommended by the President in order to gain a full appreciation of the dynamics of the current policy debate.

Among these major tenets are that:

1. Federal financial participation in the cost of the new program must be capped. As proposed by the President, the level of federal aid channeled to the states through the new home and community-based grant program would be very substantial -- more than $38 billion dollars annually once the program was fully implemented early next century. States also would qualify for an enhanced federal matching rate, compared to their current Medicaid matching ratios (essentially 28 percentage points higher than a state's FMAP rate, with a floor of 75% and a ceiling of 95%). However, annual funding levels for this new, universal HCB program would be established by law, rather than allowing the program to operate as an open-ended entitlement, similar to Medicaid and AFDC.

   The decision to frame the new program in this way represents a concession to fiscal and political realities. A nation with a $4.3 trillion debt simply cannot afford to sign any more blank checks. Besides, given the budgetary havoc they have caused at the state level over the past decade, most governors and state legislators are dead set against the creation of any new federal entitlement programs.

Paradoxically, however, the Clinton health reform legislation would retain Medicaid funding of long term care services as an open-ended entitlement, with virtually no changes in current authorizing statutes. Any one who has studied the President's proposals will recognize that this dichotomy between **a** generously funded closed-ended grant program and an open-ended entitlement program probably is not sustainable over the long haul. Indeed, until just weeks before the unveiling of the Clinton health reform plan, the Administration was prepared to propose that Medicaid HCB expenditures be folded into the new, universal HCB program authority by the end of a seven year phase-in period. Last minute objections from key Democrats in Congress convinced the Administration to back away from this aspect of its plan. Instead, the final draft legislation calls for the creation of a federal-state commission to make recommendations on Medicaid's future role in financing long term care services.

One key question, therefore, that advocates for people with developmental disabilities must consider is: **should federal financial participation in the cost of long term services be capped at some future date, how should the federal government participate in the cost of serving and supporting children and adults with developmental disabilities and their families?** Through a single, unified state grant program along the general lines proposed by the Clinton Administration? Or through a categorical state grant program which, in the case of services to people with developmental disabilities, uses current federal ICF/MR and HCB waiver payments to a state as a funding base and builds in a reasonable annual growth rate to accommodate both price inflation and the backlog of unmet service needs? Or, perhaps, through a supplement to existing cash assistance (SSI) payments to individuals, their families, where appropriate, or designated representative payees.

Interestingly, the question of whether to create a separate closed-ended grant authority for long term services to people with developmental disabilities was among the most hotly debated issues in the Clinton Administration task force that developed the LTC proposals that eventually were included in the President's health reform plan. Due in part to divisions within the disability advocacy community, the task force eventually decided to leave the financing of MR/DD services as part of a single, unified program.

A discussion of the pros and cons of seeking a separate funding stream for long term developmental disabilities services is beyond the scope of the present paper. The current national health care debate, however, should serve as **a** reminder to the disability community that the future of the Medicaid program will be determined by forces that reach far beyond the particular interests of people with developmental disabilities. It would be extremely short-sighted, therefore, to assume that federal Medicaid support for developmental disabilities services will be unaffected by the more basic changes that are likely to occur in federal policy, sooner or later, as a direct consequence of the passage of national health reform legislation. Failure to engage in the necessary dialogue now may be tantamount to allowing the future to be shaped by individuals who have far less interest in the welfare of people with developmental disabilities.

2. **Eligibility under the new, universal HCB grant program should be non-categorical but restricted to people with the most severe disabilities.** The threshold level of severity in the case of people with mental and cognitive disabilities (as well as young children) is not spelled out in the Clinton legislation; instead, the assignment of developing specific eligibility criteria would be delegated to the Secretary of Health and Human Services. The clear intent, however, is to limit participation to the segment of the disability population with the most severe disabilities. A significant percentage of individuals with developmental disabilities who currently are qualified to receive Medicaid-reimbursable ICF/MR and/or HCB waiver services, therefore, probably would not be eligible for services under the new, universal HCB program. Administration officials estimate that approximately 300,000 individuals with developmental disabilities would qualify under the new program standards; however, these estimates would remain highly speculative until the Secretary's criteria were promulgated.

   The basic question that needs to be answered is: **if the amount of federal financial assistance to be made available for home and community-based services under the Administration's proposed, new HCB grant program is to be limited (as it almost certainly will be), should the level of disability be the sole factor taken into account in determining an individual's eligibility for services?** Under the Administration's proposed legislation, participating states would be prohibited from restricting eligibility for program services on the basis of income, age, geographic considerations, the nature, severity or category of an individual's disability, or the type of residential setting (other than an institutional living arrangement) in which the individual resides. A closely related question is: are assessment techniques available (or can they be readily developed) for accurately and objectively distinguishing between the relative severity of the disabilities faced by people with widely disparate types of impairments and support needs?

3. **Under the new, universal state grant program, eligibility for federally-funded HCB services should not be subject to an economic means test.** Unlike Medicaid, eligibility for services under the Clinton Administration's new HCB grant program would not be limited to low income individuals. While the Administration's bill does include mandatory cost sharing provisions scaled to an individual's income, no one could be denied services on the basis of their economic resources. Consequently, the pool of potential recipients would be considerably larger (estimated by Administration officials as 10.1 million) than exists under current Medicaid policy. To limit the fiscal impact of a broader eligibility pool, Administration planners decided to restrict eligibility to persons with

the most severe disabilities and establish close-ended federal funding levels. Because such a comparatively high percentage of people with developmental disabilities (particularly adults) meet the Medicaid income/resources eligibility tests, they would be relatively disadvantaged by this approach to regulating program participation, especially should Medicaid HCB services eventually be consolidated under the new universal program authority.

The key public policy question is: **should an individual's income and resources be taken into account in determining his/her eligibility for federally-assisted long term care services.** Under Medicaid policies, they are; under the Administration's proposed new HCB grant program, they would not be.

Proponents of the Administration's approach argue that universal eligibility is an essential step toward decoupling long term services from **a** welfare mentality and establishing a new social contract under which the American public recognizes that everyone is at-risk of needing long term supports at some point in their lives and, therefore, should share in the cost of providing such assistance. This line of argument makes eminent sense in terms of a social insurance program, where eligibility for government-financed benefits are treated as a right of qualified recipients and tied to an actuarily sound method of financing such benefits. It does not necessarily follow that a non-means tested program, funded with general revenues, could be expanded gradually to include persons with less severe, but nonetheless disabling, conditions. Indeed, given the heavy indebtedness of the federal government and the likelihood that the national debt will continue to trend upward, the possibility of future constraints on federal funding levels would appear to be a very real possibility, even assuming that Congress were to adopt the program funding levels proposed by the President.

4. **States should be given considerable latitude in determining how services under the new, universal HCB grant program should be organized, financed and delivered.** Since federal-state resources would be inadequate to meet the needs of all eligible persons -- especially during the early years of the phase-in period -- the way in which funds were distributed among eligible target populations undoubtedly would vary considerably from state to state. In states with particularly strong MR/DD advocacy networks, for example, services to people with developmental disabilities probably would fare reasonably well. But, due to the higher marginal cost typically associated with serving this population, MR/DD services may not do nearly as well under this approach in other states.

   The critical considerations that need to be balanced off in this area of policy are: the degree of interstate varability in access to services that can be tolerated versus the need to allow each participating state sufficient operating flexibility to identify solutions that fit its own unique circumstances and needs. Fair minded people will differ on precisely where this balance point lies, but certainly it represents a key to the success of a state grant program of this type. The Clinton Administration, in its legislative specifications for the proposed new, universal HCB grant program comes down on the side of allowing the states wide-ranging discretion in organizing their HCB service delivery systems.

Conclusion

Over the past two decades, federal-state Medicaid dollars have assumed a predominant role in financing both institutional and community-based services for people with developmental disabilities. More than three out of every four public dollars expended on such services are channelled through the federal-state Medicaid program. While Title XIX funding of long term services to other populations of individuals with severe, chronic disabilities (e.g., persons who are frail and elderly or have a severe and persistent mental illness) also has grown in recent years, other sources of public and private financing play a much more prominent role in supporting services to the latter populations.

There is no question that the fundamental operating assumptions of current Medicaid law -- particularly the open-ended, entitlement basis of federal financial participation combined with the statutory latitude that states are granted in designing and operating their own respective Medicaid programs -- has fueled dramatic, nationwide changes in the composition and quality of developmental disabilities services which, quite simply, would not have occurred in the absence of Title XIX dollars. The historic shift from an institutionally-dominated service delivery system to one that is far more community-centered today than it was as recently as a decade ago is due, in no small measure, to the availability of federal-state Medicaid support.

As our national leaders begin a historic reassessment of all components of the American health care system, one issue that needs to be addressed is the locus and extent of future federal responsibility for financing long term services and supports to people with developmental disabilities. Clearly, any attempt to rewrite federal health care policies will lead, almost inevitably, to major modifications in -- indeed possibly the eventual elimination of -- the federal-state Medicaid program, at least in its present form. Certainly, we can assume that three of the overriding objectives of any legislative reforms in Medicaid policy will be to: (a) blend basic health care services for low income individuals and families into the mainstream of a restructured American health financing and delivery system, rather than retaining a separate federal-state program for the poor; (b) reign in the runaway costs of Medicaid services in order to bring a much needed sense of stability to federal and state budgets; and (c) rationalize the hodge-podge of policies that currently govern Title XIX-financed long term care services, with primary emphasis on allowing people with chronic disabilities to receive needed assistance in their own homes and communities whenever possible. These objectives, obviously, are not necessarily mutually compatible and, consequently, it would be foolish in the current unsettled policy environment to assume that federal Medicaid support for developmental disabilities services will be unaffected by the more basic changes that are likely to occur in federal Medicaid policy as a result of national health reform legislation.

This paper has been an attempt to delineate some of the key national policy issues that will have to be resolved in formulating future long term care policies that impact on people with developmental disabilities. It is the author's fervent hope that the issues identified here will contribute in some small measure to the dialogue that needs to take place among leaders in the field if millions of individuals with lifelong disabilities are to gain access to the supports necessary to live rich and fulfilling lives in their own communities.

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