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Disability and the managed care frenzy: a cautionary note
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While the fortunes of national health care reform rose and fell in 1993-1994, private-sector managed care organizations were transforming the American health care system. More than half of the employed population is now enrolled in managed care plans, and the consensus among private employers seems to be that managed care is working well for them.

Persons with disabilities are a small but significant subpopulation of health care consumers. Approximately thirty-seven million persons age fifteen or older are estimated to have at least one physical disability; more than seven million of these persons require help with everyday activities. In fiscal year 1992, 3.6 million (nonelderly) physically and mentally disabled persons qualified for participation in Medicare. This 10 percent of program beneficiaries accounted for 14 percent of Medicare expenditures, or some $17 billion. In the same year nonelderly Medicaid recipients with physical and mental disabilities comprised 14.4 percent of the Medicaid population but incurred more than 37 percent of program costs.

Persons with disabilities are at once the best and the worst managed care clientele. They have much to gain from a truly and responsively integrated delivery system. They also, however, bring atypical and complex service needs to managed care and may introduce an element of unwelcome clinical and financial risk. Nevertheless, the rush to managed care, even on the part of public programs for which persons with disabilities are a major constituency, proceeds apace.

This Commentary sounds a cautionary note. We rehearse the logical incompatibilities of managed care and health care financing and delivery for persons with disabilities and review the documented experience to date. We argue that a policy of serving this population, especially disabled Medicaid recipients, in managed care organizations is fraught with foreseeable complexity. Although we neither support nor oppose the ardent em-
brace of managed care by health care reformers, we do urge sober anticipa-
tion of the “morning after.” No matter how well intended, the actual
practice of managed care for persons with disabilities at best will test the
patience and ingenuity of all involved.

**Medicaid And Persons With Disabilities**

The Medicaid program provides significant funding for the care of per-
sons with disabilities. It also has directed the conversion of large numbers of
recipients, primarily the Aid to Families with Dependent Children
(AFDC) population, to membership in managed care organizations. Medicaid managed care for persons with disabilities, however, will be more
challenging than the AFDC experience, in part because of the program’s
unique commitment to disabled persons. First, Medicaid typically serves
the most vulnerable persons with disabilities-low-income persons with
severe disabilities-and, in some states, uninsured persons with severe
disabilities who become eligible by “spending down” their income and
assets on medical necessities. Medicare eligibility for persons with disabili-
ties, in contrast, requires a level of previous workforce participation and a
two-year waiting period. Even those who eventually will become Medicare
beneficiaries often receive Medicaid benefits first.

Furthermore, Medicaid covers distinctively disability-sensitive serv-
ices-a more inclusive and functionally oriented set of benefits than, say,
Medicare or standard commercial insurance plans cover. In addition to
conventional medical care, Medicaid programs may cover, for example,
residential facilities for persons with developmental disabilities, personal
care, pharmaceuticals, and, under various waivers of program regulations,
customized packages of home care, including homemaker services and
environmental adaptation. The idiosyncracies of Medicaid financial eligi-
bility-namely, that institutionalized children are not considered to share
their parents’ income, and that potential institutionalization may substitute
for actual institutionalization-have created a subpopulation of middle-
class children with disabilities who receive intensive Medicaid-covered
home care in their parents’ non-Medicaid-eligible households.

Medicaid also has been an important locus of service and system devel-
opment for particular disabled subpopulations. The home and community-
based waiver authority was instrumental in the deinstitutionalization of
technology-dependent children both to their own families and to foster
care. The availability of regular Medicaid-covered services such as personal
care, occupational therapy, and prescription drugs allowed state agencies
with mentally ill, developmentally disabled, and human immunodeficiency
virus (HIV)-positive constituencies to establish community-based congre-
gate living arrangements. Even Medicaid coverage of treatment in intermediate care facilities for the mentally retarded (ICF-MR) has had a salutary influence on the service delivery system: as incentive for institutions to meet basic standards, for facilities to undertake “active treatment,” and for states to fund a community-based “habilitation” benefit.

Managed care, however, typically has not been part of the Medicaid program’s disability-oriented service array. Because managed care organizations flourish when (unnecessary) utilization is minimized, disabled recipients—especially those with chronic illnesses—carry unwanted risk. Also, managed care organizations’ emphasis on primary care and limited access to specialty care may threaten the ongoing specialist/patient relationships of some disabled Medicaid recipients. Studies of other low-income, chronically ill populations enrolled in managed care suggest that persons with disabilities on Medicaid will not be easily served.  

Medicaid managed care for persons with disabilities is under active consideration in many states, but where it has been initiated, the results have been tentative and mixed. Early demonstration programs in Santa Barbara, California, and in Minneapolis came into conflict with both advocacy groups and managed care plans, specifically regarding providers’ readiness to serve disabled populations. Major structural changes were made to remove impediments to disability-specific providers in Santa Barbara, while in Minneapolis managed care enrollment was converted from mandatory to voluntary status. Recent efforts under the Section 1115 “super-waivers” indicate that many of these earlier difficulties persist. A study of sixteen states in which disabled Medicaid recipients were enrolled in managed care plans without a Section 1115 waiver found partial and problematic implementation overall. Owing mostly to hesitant and ill-equipped plans, some states enrolled persons with disabilities who quickly disenrolled, while recipients in one state were enrolled but could not avail themselves of services.

Managed Care And Persons With Disabilities

Medicaid policy is only one complicating factor in managed care for persons with disabilities. It is also problematic for other organizational, fiscal, and clinical reasons.

Organizational issues. Managed care may remedy the fragmented service delivery afflicting some persons with disabilities in the fee-for-service system. In managed care, care coordination is commonly directed by the patient’s primary care physician. Moreover, many integrated systems offer comprehensive service centers and may even provide transportation between enrollees’ homes and this facility. Such logistical amenities may
greatly enhance the accessibility of care, especially for persons with limited physical mobility. For Medicaid recipients, moreover, access to care—especially physician services—has always been constrained. Because beneficiaries with disabilities typically require the services of multiple physicians and other providers, a managed care organization may mobilize its referral network to fulfill an as yet unfulfilled entitlement.

On the other hand, most disabled Medicaid recipients now secure care somewhere. If they require highly specialized care, they may be receiving it in traditionally service-rich settings, such as academic medical centers or clinics organized by disability-specific voluntary or governmental organizations—for example, United Cerebral Palsy or Title V (“Crippled Children”) agencies. These entities, in turn, not only are unlikely to be active members of managed care networks, but they also may not have accommodated themselves to risk management, capitated payment, and other more commercial aspects of health care delivery. The same of course may be true of persons with disabilities. The resource-conserving ethos of managed-and especially capitated—care is understandably suspect among those potential enrollees who already face disability-related obstacles to service use. Indeed, some disability advocacy groups have spoken out publicly against enrollment in managed care organizations.

Managed care organizations that do enroll persons with disabilities must provide for many serious and distinctive health care needs. Most managed care organizations have limited experience with disabilities and will have to seek out additional specialists and disability-experienced generalists. One study of disabled children enrolled in health maintenance organizations (HMOs) found the most serious disadvantage of managed care to be insufficient access to specialty providers. Similarly, managed care organizations are unlikely to have well-developed relationships with providers of the specialized ancillary services that persons with disabilities use, for example, wheelchair manufacturers, home infusion therapists, and personal care attendants.

Alliances between commercial managed care organizations and traditional sources of care for persons with disabilities may succeed in mitigating these incompatibilities. The Medicaid Working Group, a Boston-based team funded by The Robert Wood Johnson Foundation and The Pew Charitable Trusts to develop, in cooperation with states, innovative models of managed care for disabled Medicaid recipients, has found the most promising models to comprise partnerships between commercial HMOs and academic medical centers or community service organizations. Although these arrangements are still in the early stages of implementation, the partners seem willing to trade commercial for clinical expertise and to create mechanisms for shared decision making when clinical matters be-
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come commercial ones and vice versa.

**Fiscal issues.** Managed care usually entails capitation, and capitated reimbursement works best when utilization is predictable for members and only modestly variable among them. Medicaid Working Group analysts found that although year-to-year use by disabled persons is fairly stable, the variability among disabled persons is much greater than in the general population or among other Medicaid recipients. Setting capitation rates for Medicaid beneficiaries with disabilities, then, entails more refined risk categories than those to which state agencies and managed care plans are accustomed.

Expenditure variability among persons with disabilities is hardly surprising, given the range of medical conditions represented by this population. It is not at all clear, however, that diagnosis will prove to be the best predictor of cost. In fact, the Medicaid Working Group’s earliest efforts have produced a rate schedule based on previous program expenditures that outperforms a diagnosis-based alternative, although when ratesetters are able to adjust for severity, for example, diagnosis may surpass experience. Some managed care organizations enroll persons with disabilities under partial capitation arrangements, thereby minimizing providers’ vulnerability to inadequate risk adjustment. Similarly, states participating in the Medicaid Working Group Project have defined the contractual risk corridors such that the Medicaid agency assumes most of the financial risk.

Despite its technical importance, risk adjustment is unlikely to be the factor on which managed care for persons with disabilities turns. As are other health insurers, managed care organizations are risk-averse, however actuarially sound their premiums, and capitated plans can always discourage enrollment by persons with disabilities, who may be seen as prone to high levels of use. Ironically, in this self-protective environment, organizations offering specialized or disability-sensitive care may attract more than their share of the neediest patients—patients whose legitimate claims on the system will sink these praiseworthy providers. Furthermore, the participation of multiple payers for persons with disabilities makes for administrative complexity and some perverse incentives. In states where persons with disabilities “spend down” their funds to Medicaid eligibility, for example, managed care organizations will have to manage continuous-or not so continuous-part-month enrollment. Capitated Medicaid recipients who are also fee-for-service Medicare recipients, moreover, may find that they are hospitalized with greater frequency than their Medicaid-only peers.

**Clinical issues.** At its purest, the logic of managed care holds that patients are well served when providers maintain fiscal accountability through capitation but are freed from the bureaucratic service limitations, paper trails, and other strictures of fee-for-service medicine. Disabled per-
sons might be especially well served under such conditions, that is, when physicians design customized care plans, drawing from a complete array of services, based on an ongoing knowledge of patients, and with the many presumed efficiencies of a less administratively encumbered care setting.

The design of innovative clinical models under managed care, however, is still in its infancy, and it is not an established feature of plans currently serving or planning to serve Medicaid recipients with disabilities. The Medicaid Working Group heralds the clinically liberating potential of capitated payment; participating states require a commitment to disability-responsive care from their contracting plans. Still, it remains to be seen whether plans will (be able to) comply in the long run. The most promising models include customized interprofessional care teams and extensive use of home-based services. However, large commercial plans may balk at exceptions for this single enrollee group, and even a disability-specific plan will be constrained by prevailing scope-of-practice regulations and the supply of home care services.

A largely neglected influence on clinical models is the tenor of patient/provider relationships, specifically, the terms on which patients participate in their own care. These terms are especially salient in managed care, where payer and provider may be a single entity with an incentive to underserve, and in the care of persons with disabilities, who are “expert” in their disabling conditions and resultant functional needs. The complexity of these relationships is already manifest. One study found HMOs to surpass fee-for-service medicine on coordination but not on accountability. Another found that even (especially) in highly coordinated managed care arrangements, disabled children whose parents took on the system did better than those whose parents did not. Responsiveness, apparently, is not an all-or-nothing affair, and managed care for persons with disabilities will have to negotiate subtle and dynamic needs for assistance and independence.

Conclusion

As both the best and worst managed care clientele, persons with disabilities are at a special kind of risk. Recent developments in Medicare and Medicaid portend expedited managed care enrollment, and the potential benefits of managed care for persons with disabilities may accelerate—or at least legitimate—the rush by public sponsors to these arrangements. The real complexities and potential liabilities of managed care for persons with disabilities, however, suggest a more cautious approach. The challenges are both foreseeable and unforeseen, and we are obligated to attend to the former even in the short run.
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NOTES


15. Ibid.
