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Medicaid Managed Care and People with Disabilities: Challenges and Opportunities

By Sarah Somers and Jane Perkins



Sarah Somers
Staff Attorney

Jane Perkins
Legal Director

National Health Law Program
211 N. Columbia St. 2d Floor
Chapel Hill, NC 27516

somers@healthlaw.org
919.968.6771 ext. 103

perkins@healthlaw.org
919.968.6308 ext. 102

As states grapple with the costs and the administrative challenges of delivering Medicaid services, managed care has become the prevailing service delivery model in Medicaid. Most Medicaid-eligible families with children are now enrolled in managed care plans. States and managed care providers are increasingly interested in moving people with disabilities into managed care. This trend presents both opportunities and risks for Medicaid beneficiaries and their advocates. Policy-makers and advocates need to understand these potential advantages and disadvantages in order to avoid problems for Medicaid beneficiaries. What are the basic rules governing Medicaid managed care? What issues in managed care are related to serving people with disabilities? What principles should states follow when determining whether and how to provide Medicaid benefits through managed care for people with disabilities?

I. Basic Rules

Medicaid is the cooperatively funded federal-state program that covers health insurance for low-income people.¹ Founded in 1965, it is the primary source of insurance for millions of Americans. The federal government reimburses states that participate in the program for at least half of all of their expenditures under the program. The states do not provide services directly to Medicaid beneficiaries but pay private providers for those services.

Medicaid requires states to provide eligibility for certain categories of individuals with the option of covering others.² Similarly states must cover certain services and have the option of covering others.³ Medicaid beneficiaries generally have the right to obtain services from any qualified, Medicaid-participating provider—a right called freedom of choice.⁴ However, Medicaid beneficiaries have been allowed to enroll voluntarily in qualified managed care plans since the early days of the program. When they elect to enroll in a managed care plan, they give up their freedom of choice.

The Medicaid Act was amended in 1976 to establish standards for managed care organizations and other prepaid entities participating in Medicaid.⁵ Regarding managed care organizations (commonly referred to as MCOs), the legislation prohibits federal funding to states unless the contracts between the states and MCOs and the

¹Title XIX of the Social Security Act, 42 U.S.C. §§ 1396-1396v (2007); 42 C.F.R. § 430 (2006). For an in-depth discussion of the Medicaid program, see JANE PERKINS & SARAH SOMERS, NATIONAL HEALTH LAW PROGRAM, AN ADVOCATE'S GUIDE TO THE MEDICAID PROGRAM (2001).

²42 U.S.C. § 1396a(a)(10)(A) (2007).

³*Id.* § 1396d(a).

⁴See *id.* § 1396a(a)(23) (the "freedom of choice" rule).

⁵S. REP. NO. 95-749 (1978); H.R. REP. NO. 94-1513 (1976) (conference report), reprinted in 1976 U.S.C.C.A.N. 4371. See also Andreas Schneider & Joanne Stern, *Health Maintenance Organizations and the Poor: Problems and Prospects*, 70 NORTHWESTERN UNIVERSITY LAW REVIEW 90, 126-38 (1975).

MCOs themselves adhere to minimum accountability and stewardship protections.⁶ Among other provisions, the contracts between the state and each MCO must assure that the organization does not discriminate on the basis of health status or need, that beneficiaries have the right to disenroll, that the state has the right to audit and inspect the books and records of the organization, and that the organization maintains adequate patient encounter data to identify the providers who deliver the services to patients.⁷ Other managed care entities are not subject to these strictures.

In the early 1980s Congress and the Reagan administration enacted legislation to encourage increased enrollment in Medicaid managed care plans. The Omnibus Budget Reconciliation Act of 1981 (OBRA-81) added Section 1915(b) to the Social Security Act.⁸ Section 1915(b) allows states to request that the U.S. Department of Health and Human Services (HHS) waive otherwise mandatory Medicaid provisions, and thus the states may require beneficiaries to enroll in a managed care plan. Under the law, HHS must find the proposed program to be cost-effective, efficient, and not inconsistent with the purposes of the Medicaid program. MCOs and other systems that restrict freedom of choice cannot apply to emergencies or family planning services and cannot “substantially impair access to services of adequate quality where medically necessary.”⁹ Moreover, restrictions cannot “discriminate among

classes of providers on grounds unrelated to their demonstrated effectiveness and efficiency in providing services.”¹⁰

Significant changes were also introduced by the Balanced Budget Act of 1997.¹¹ That Act authorizes states to implement mandatory managed care for most Medicaid population groups through a simple state-plan amendment.¹² A waiver is not required. Some population groups, however, are excluded from the state-plan option. States must still obtain waivers to require the following population groups to enroll in Medicaid managed care:

- Children under 19 with special needs if they are eligible for Supplemental Security Income (SSI), if they are described in community-based care programs under Title V of the Social Security Act, if they are eligible through the “Katie Beckett” option, or if they are in foster care, adoption assistance, or out-of-home placement.¹³
- Qualified Medicare Beneficiaries or persons dually eligible for Medicare and Medicaid.
- Native Americans (unless the managed care entity is operating as part of Indian Health Services).¹⁴

Since the early 1980s, the number of Medicaid managed care arrangements and the number of beneficiaries enrolled in them have increased: In 1981 only 1.3 percent of the total Medicaid population was enrolled in some sort of managed

⁶See 42 U.S.C. § 1396b(m) (2007).

⁷*Id.*

⁸Omnibus Budget Reconciliation Act of 1981, Pub. L. No. 97-35 § 2715(a), 95 Stat. 809, 42 U.S.C. § 1396n(b) (2007).

⁹42 U.S.C. § 1396n(b)(2) (2007).

¹⁰*Id.* § 1396n(b)(4) (2007). The U.S. Department of Health and Human Services also has authority to approve demonstration waivers, which may cover managed care programs. See *id.* § 1315 (Section 1115 of the Social Security Act).

¹¹Balanced Budget Act of 1997, Pub. L. No. 105-33 (1997).

¹²See 42 U.S.C. § 1396u-2 (2007).

¹³Title V of the Social Security Act, 42 U.S.C. §§ 701–710 (2007); *id.* § 1396a(e) (the “Katie Beckett” option allows certain disabled children to be treated and to live at home instead of in an institution even though their parents’ income would otherwise make them ineligible for such coverage).

¹⁴*Id.* § 1396u-2(a)(2). See, e.g., *Hawkins v. El Paso First Health Plans Incorporated*, 214 S.W.3d 709 (Tex. Ct. App. 2007) (determining whether infants eligible for Supplemental Security Income may be retroactively disenrolled from managed care organizations).

care program.¹⁵ By 1997 this percentage had swelled to approximately 48 percent of all beneficiaries, and in 2006 no less than 65 percent of beneficiaries were enrolled in a managed care program.¹⁶ All states except Alaska and Wyoming enrolled at least some Medicaid beneficiaries in some type of managed care program. Thus most beneficiaries are now enrolled in a managed care plan.¹⁷

Currently three basic types of managed care entities provide services through Medicaid: MCOs, prepaid health plans (commonly referred to as PHPs), and primary care case management providers (commonly referred to as PC-CMs). MCOs are divided into two types, commercial and Medicaid-only, and include health maintenance organizations, Medicare+Choice organizations, and provider-sponsored organizations.¹⁸ Generally Medicaid MCOs provide enrollees with a specified package of Medicaid services in exchange for a fixed, prepaid “capitation payment” per enrollee.¹⁹ MCOs may engage in comprehensive risk contracts. This means that they assume responsibility for providing services in return for a fixed rate, regardless of actual costs of services provided.²⁰ These contracts cover comprehensive services, including inpatient hospital services and any of the following: (1) outpatient hospital services; (2) rural health clinic services; (3) Federally Qualified Health Center services; (4) laboratory and X-ray services; (5) nursing facility services; (6) early and periodic screening, diagnos-

tic and treatment; (7) family planning services; (8) physician services; and (9) home health services.²¹

Prepaid health plans, in contrast, provide less than comprehensive benefits on an at-risk basis or other basis that does not include state reimbursement for services. Through regulations, HHS established two types of PHPs: prepaid inpatient health plans and prepaid ambulatory health plans. Prepaid inpatient health plans provide, arrange for, or otherwise have responsibility for the provision of any inpatient hospital or institutional services. Prepaid ambulatory health plans deal with services that are not inpatient services.²²

Under “primary care case management,” a primary care case management provider contracts with the state to furnish case management services to Medicaid recipients. A PCCM, in contrast to MCOs and PHPs, is typically paid a monthly fee per enrollee to provide case management services and receives payment for services it provides. In most states with PCCMs, enrollment is mandatory.²³ Case management services include locating, coordinating, and monitoring primary and specialty care health services.²⁴ A PCCM can be a physician, a physician group practice, or other entity employing physicians to provide primary care. At the state’s option, a PCCM can also include a physician assistant, nurse practitioner, or a certified midwife.²⁵ As of 2002, two-thirds of all PCCMs used

¹⁵CENTERS FOR MEDICARE AND MEDICAID SERVICES, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, 2006 MEDICAID MANAGED CARE ENROLLMENT REPORT: SUMMARY STATISTICS.

¹⁶*Id.*

¹⁷*Id.* at 4–5.

¹⁸42 U.S.C. § 1396b(m)(1)(A) (2007).

¹⁹See *id.* § 1396u-2(b).

²⁰42 C.F.R. § 438.2 (2006).

²¹*Id.*

²²*Id.*

²³NEVA KAYE, NATIONAL ACADEMY FOR STATE HEALTH POLICY, MEDICAID MANAGED CARE: LOOKING FORWARD LOOKING BACK 30 (2005), www.nashp.org/Files/mmc_guide_final_draft_6-16.pdf. (last visited June 26, 2007).

²⁴42 C.F.R. § 438.2 (2006).

²⁵42 U.S.C. § 1396d(t)(4) (2007); 42 C.F.R. § 438.2 (2006). See also CENTERS FOR MEDICARE AND MEDICAID SERVICES, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, STATE MEDICAID DIRECTOR LETTERS (1998), www.cms.hhs.gov/SMDL/01_overview.asp#TopOfPage; KAYE, *supra* note 23, at 41–42.

nonphysicians as primary care case managers.²⁶ For example, twenty-one states specifically allow rural health clinics to be PCCMs, thirteen allow Indian Health Services facilities, six allow maternal and child health clinics, and four allow school-based health clinics.²⁷

Primary care from PCCMs includes all health care and laboratory services customarily provided through a general practitioner, family medicine physician, internal medicine physician, obstetrician, gynecologist, or pediatrician. PCCMs are not all alike but share common elements. For example, all currently operating PCCMs are required to offer access to care on a twenty-four-hour, seven-day-a-week basis.²⁸ Also, a PCCM by contract must

- have adequate hours of operation, with twenty-four-hour availability of emergency information, referrals, and services;
- restrict enrollment to individuals living near the service delivery site;
- arrange with or refer to sufficient numbers of physicians and health care professionals to ensure prompt delivery of services;
- prohibit discrimination on the basis of health status in enrollment, disenrollment, and reenrollment; and
- allow an enrollee to disenroll.²⁹

Primary care case management services are prevalent in states (particularly in rural areas) where the Medicaid agency is having difficulty attracting commercial health plans to the Medicaid system.³⁰ As of June 2006, twenty-eight states were operating primary care case management services.³¹ In a number of states—Alabama, Arkansas, Idaho, Louisiana, Montana, Oklahoma, South Dakota, and Utah—most Medicaid managed care was administered through primary care case management services, and no Medicaid services were delivered through MCOs.³²

II. Medicaid Managed Care for People with Disabilities

An estimated fifty-three million Americans have a physical or mental disability, and Medicaid covers nearly one-third of them.³³ Medicaid covers more than a dozen separate categories of people with disabilities—people receiving SSI; people living in nursing facilities, hospitals, or intermediate care facilities; and other low-income disabled individuals, among others.³⁴ The range of people who have disabilities and need Medicaid encompasses medically fragile and ventilator-dependent children, people with intellectual disabilities and other developmental disabilities, mental illness, traumatic brain and spinal cord injuries, and chronic conditions ranging from diabetes to AIDS (autoimmune deficiency syndrome).³⁵

²⁶KAYE, *supra* note 23, at 73.

²⁷*Id.* This means that the state designated these providers specifically as primary care case management (PCCM) entities and not simply that they allowed individual physicians working in one of these settings to act as PCCM providers. Individual physicians may, and usually do, work in these entities but are not identified individually as the actual PCCM.

²⁸ROBIN K. COHEN, CONNECTICUT GENERAL ASSEMBLY OFFICE OF LEGISLATIVE RESEARCH, RESEARCH REPORT: PRIMARY CARE CASE MANAGEMENT IN MEDICAID, www.cga.ct.gov/2006/rpt/2006-R-0550.htm (last visited Sept. 27, 2006).

²⁹42 U.S.C. § 1396d(t)(3) (2007).

³⁰Eric C. Schneider, *Quality Oversight in Medicaid Primary Care Case Management Programs*, 23 HEALTH AFFAIRS 235 (2004).

³¹CENTERS FOR MEDICARE AND MEDICAID SERVICES, *supra* note 15, at 6; see also Schneider, *supra* note 30, at 240.

³²CENTERS FOR MEDICARE AND MEDICAID SERVICES, *supra* note 15, at 6.

³³HENRY J. KAISER FAMILY FOUNDATION, NAVIGATING MEDICARE AND MEDICAID: A RESOURCE GUIDE FOR PEOPLE WITH DISABILITIES, THEIR FAMILIES, AND THEIR ADVOCATES 1 (2005).

³⁴42 U.S.C. §§ 1396a(a)(10)(A)(i)–(ii) (2007); see also PERKINS & SOMERS, *supra* note 1, ch. 3.

³⁵See, e.g., KAISER COMMISSION ON MEDICAID AND THE UNINSURED, MEDICAID'S ROLE FOR PEOPLE WITH DISABILITIES (2003).

People with disabilities also make up an increasing proportion of the Medicaid managed care population. Moreover, the vast majority—approximately 78 percent—of Medicaid beneficiaries with disabilities receive SSI.³⁶ For example, in 2002, more than thirty-five states reported enrolling SSI-eligible individuals in managed care.³⁷ Many of these SSI-eligible individuals were required to enroll.³⁸ At the same time, however, many states recognize that the needs of some population groups, such as individuals eligible under both Medicare and Medicaid, cannot be met by managed care and allow them to remain in fee-for-service programs.³⁹

States seek to enroll the disabled in managed care programs because providing Medicaid coverage to people with disabilities is costly. People with disabilities are frequent users of health care services and need the services of multiple providers in various settings. In fact, in 2002, while people with disabilities made up only 16 percent of the Medicaid population, they accounted for 43 percent of the expenditures.⁴⁰ Saving money is one of the most common motivations for states to turn to managed care in Medicaid. Not surprisingly, states seeking to gain control of their Medicaid budgets want people with disabilities to enroll in managed care. This can, however, present serious problems.

For example, requiring people with disabilities to enroll in managed care could lead to decreased quality of services. First, people with disabilities may not be able to obtain necessary specialty care due to the limits on provider choice. Second, if people with disabilities are required

to move from fee-for-service care, they may have to end relationships with current providers. And, third, in the interest of controlling costs, managed care entities may fail to provide the full scope of services mandated by federal Medicaid law. This can, of course, be especially problematic for people with disabilities. Indeed, Medicaid is a crucial source of insurance for people with disabilities, in large part because Medicaid does not have lifetime limits on coverage as private insurance does. Thus plans limiting the scope of available services are particularly harmful for this population.

To remedy such problems, managed care enrollees have had to resort to litigation. For example, *John B. v. Menke* was filed in 1998 on behalf of a class of Medicaid beneficiaries under 21, a number of whom had disabilities, to challenge Tennessee's managed care system.⁴¹ This system, known as TennCare, had essentially replaced the state's traditional Medicaid program.⁴² TennCare is a capitated system in which the state contracts with individual MCOs to provide all medically necessary services. TennCare also gave responsibility for substance abuse and behavioral health services to behavioral health organizations. The plaintiffs alleged that Tennessee failed to comply with Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) requirements applicable to all Medicaid beneficiaries under 21.⁴³ A consent decree was reached in 1998.⁴⁴ Plaintiffs returned to court in 2001 to challenge the state's failure to comply with the consent decree. The court held that, indeed, Defendants were not complying with the 1998 consent decree.⁴⁵

³⁶JANET B. MITCHELL ET AL., RTI INTERNATIONAL, ACCESS TO CARE FOR MEDICAID BENEFICIARIES WITH DISABILITIES IN RURAL KENTUCKY (2004).

³⁷KAYE, *supra* note 23, at 2.

³⁸*Id.*

³⁹*Id.*

⁴⁰KAISER COMMISSION ON MEDICAID AND THE UNINSURED, *supra* note 35, at 21.

⁴¹*John B. v. Menke*, 176 F. Supp. 2d 786 (M.D. Tenn. 2001).

⁴²*Id.* at 788.

⁴³*Id.* at 790; 42 U.S.C. §§ 1396a(a)(43), 1396d(a)(4)(A), 1396d(r) (2007).

⁴⁴*John B. v. Menke*, No. 3-98:0168 (M.D. Tenn. Mar. 11, 1998) (order approving consent decree).

⁴⁵*Menke*, 176 F. Supp. 2d at 790.

The court held specifically that the state’s attempts to comply with the consent decree’s requirements for the provision of necessary treatment had been “undermined by the MCOs and [behavioral health organizations].”⁴⁶ The court noted the pitfalls of managed care:

[M]anaged care creates incentives for cutting costs and denial of care. However, commentators have rightly observed that managed care, at least in theory, would appear to be an ideal model for the delivery of EPSDT services because it promotes preventive and primary care. However, in practice, the first of these incentives appears to outweigh the latter. In practice, MCOs and [behavioral health organizations] do not appear to take a long-term approach to the provision of EPSDT services in order to prevent future expenditures....⁴⁷

The court ordered the appointment of a special master to help ensure future compliance. The case continues, as do the disputes about compliance.

Lack of access to specialists or to providers with whom a beneficiary has a longstanding relationship can also cause serious concerns. For example, in *Hyden v. New Mexico Human Services Department*, the plaintiff was attempting to access an out-of-network allergist.⁴⁸ Plaintiff was disabled and receiving SSI. Among other conditions, she had multiple chemical sensitivity disorder. None of the three allergists to whom her MCO had referred her had been able to treat her effectively.

The MCO refused her request for an out-of-network specialist.⁴⁹ She requested a fair hearing before an administrative hearing officer but was denied. The court found that the New Mexico regulations required the MCO to have a system to refer individuals outside the network. Thus, the court reasoned, the refusal to allow a beneficiary to access appropriate treatment was a denial for purposes of triggering a fair hearing.⁵⁰

Despite these concerns, the use of managed care in Medicaid also has the potential to improve care for people with disabilities. Because of their complex needs, this population can particularly benefit from more active management of care. Many people believe Medicaid managed care plans will soon add coordination of services to their menu of services. This means coordination of not only medical but also nonmedical care. For example, some Medicaid managed care plans work with community-based organizations to coordinate transportation or to help homeless people gain access to a place to refrigerate medication.⁵¹ Many Medicaid agencies require that managed care entities provide “enabling” services, which help beneficiaries access primary services. These services are targeted for population groups with special needs—people, among them, with disability and chronic illness. Examples of enabling services are interpreter services (for individuals with hearing impairments as well as limited English proficiency), home visits, and nonemergency transportation.⁵²

Care coordination, case management, disease management, and assessments of needs were provided in more than half of states’ risk-based programs.⁵³ For ex-

⁴⁶*Id.* at 798.

⁴⁷*Id.* at 801 (citing U.S. GOVERNMENT ACCOUNTABILITY OFFICE, NO. GAO-010749, MEDICAID: STRONGER EFFORTS NEEDED TO ENSURE CHILDREN’S ACCESS TO HEALTH SCREENING SERVICES (2001)).

⁴⁸*Hyden v. New Mexico Human Services Department*, 16 P.3d 444 (N.M. Ct. App. 2000).

⁴⁹*Id.* at 19–20.

⁵⁰*Id.* at 24.

⁵¹KAYE, *supra* note 23, at 73.

⁵²*Id.* at 76.

⁵³*Id.* at 77. For more information about disease management programs, see MANJU KULKARNI, NATIONAL HEALTH LAW PROGRAM, Q & A: EVALUATING DISEASE MANAGEMENT UNDER MEDICAID (2004), www.healthlaw.org.

ample, when Oklahoma began enrolling individuals in MCOs as well as PCCMs, the Medicaid agency identified exceptional-needs coordinators of resources and special services for those with special needs.⁵⁴ The state agency engaged in staff education, conducted health fairs and informational events in accessible locations, and targeted outreach to Medicaid beneficiaries with high utilization of services.⁵⁵

PCCMs in particular have the potential to improve service delivery for people with disabilities. A health care provider serves as the “gatekeeper” in primary care case management; thus care is managed from a clinical perspective rather than simply from a business or cost-savings motivation. Moreover, the intent behind this system is for PCCMs to create a “medical home” as a source of regular and stable health care, complete with case management services. PCCMs can also offer disease and case management and health education.⁵⁶ At the same time PCCMs do not enter into risk contracts and are reimbursed for all of the care they provide. Thus they have less incentive to deny medically necessary care in an effort to save money. They are also free to refer individuals to any specialist who accepts Medicaid, in contrast to MCOs, which

refer within their capitation payments and only to providers in their network.

III. Guiding Principles

Surveys of state Medicaid plan officials and various studies identify a number of key factors in the success of managed care for people with disabilities. For example, state planning is key in ensuring that managed care works for people with disabilities. Needs assessment—a part of planning—should be required of managed care programs.⁵⁷ Investment of resources is necessary since state officials frequently report the need for considerable additional staff with expertise in such matters as rate setting, contracting, appeal and grievance procedures, and, of course, care for people with disabilities.⁵⁸ Increased oversight—quality management and provider reporting—is considered desirable.⁵⁹ And so are early intervention and care to prevent the deterioration of conditions and access to urgent care on a twenty-four-hour, seven-day basis.⁶⁰

Advocates identify a number of principles to which policymakers should adhere when considering whether to enroll people with disabilities in managed care.⁶¹

⁵⁴JOANNE RAWLINGS-SEKUNDA ET AL., NATIONAL ACADEMY FOR STATE HEALTH POLICY, EMERGING PRACTICES IN MEDICAID PRIMARY CARE CASE MANAGEMENT PROGRAMS (2001).

⁵⁵*Id.*

⁵⁶E.g., North Carolina’s Access program “is designed to provide a more efficient and effective healthcare delivery system for Medicaid recipients.... [It] brings a system of coordinated care to the Medicaid program by linking each eligible recipient with a primary care provider ... who has agreed to provide or arrange for healthcare services for each enrollee. By improving access to primary care and encouraging a stable doctor-patient relationship, the program helps to promote continuity of care, while reducing inappropriate utilization and controlling costs.” NORTH CAROLINA, DIVISION OF MEDICAL ASSISTANCE, SUMMARY OF NORTH CAROLINA’S MANAGED CARE PROGRAMS, www.ncdhhs.gov/dma/mangcarewho.html#sum (last visited March 27, 2007).

⁵⁷SARA ROSENBAUM ET AL., SCHOOL OF PUBLIC HEALTH AND SERVICES, GEORGE WASHINGTON UNIVERSITY MEDICAL CENTER, MANAGED CARE AND MEDI-CAL BENEFICIARIES WITH DISABILITIES: ASSESSING CURRENT STATE PRACTICE IN A CHANGING FEDERAL POLICY ENVIRONMENT 13 (2006), www.calendow.org/reference/publications/pdf/npolicy/ManagedCareMedi-Cal062706.pdf.

⁵⁸*Id.* at 14.

⁵⁹*Id.*

⁶⁰Henry T. Ireys et al., *Medicaid Managed Care and Working-Age Beneficiaries with Disabilities and Chronic Illnesses*, HEALTH CARE FINANCING REVIEW, Fall 2002, at 27, 29.

⁶¹Adapted from CALIFORNIA FOUNDATION FOR INDEPENDENT LIVING CENTERS, PRINCIPLES PROTECTING MEDI-CAL BENEFICIARIES WITH DISABILITIES (2005), www.cfildc.org/site/apps/nl/content2.asp?c=ghKRI0PDloE&b=868323&ct=1145223. These principles were drafted by Randy Boyle (National Health Law Program), Rhys Burchill, Maria Iriarte (Protection and Advocacy, Inc.), June Kailes (Center for Disability Issues and the Health Professions), Gabrielle Marcus (Disability Rights Advocates), Laura Remson Mitchell (California Disability Alliance), Debora Kaplan (World Institute on Disability), Curtis Richards (Advocate), Burns Vick, and the California Foundation for Independent Living Centers.

1. *Improved access, rather than cost savings, should be the motivation for moving people with disabilities into managed care.* Policymakers should not expect immediate savings to result from moving people with disabilities into managed care. Moreover, any cost savings that result from the shift to managed care should be kept within the system to improve the availability and quality of health care services for persons with disabilities.
2. *States should take advantage of the opportunity to improve health care for people with disabilities and tailor their programs to their needs.* States should, for example, work on coordinating care as well as ensuring an adequate network of providers.
3. *Keeping people with disabilities healthy and able to function in their communities should be the primary goal.* Managed care services must include access to specialists, assistive technology, and community-based services and must be designed to discourage institutional bias.
4. *Compliance with the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and any state civil rights laws must be required and monitored.*⁶² The state should describe how it plans to monitor compliance and respond to reports and evidence of disability discrimination. Managed care entities should also monitor their contractors' compliance. The state should provide resources and technical support to enable small providers to comply with these laws. Such resources and support should include sign-language interpreters and assistive listening technology for people who are deaf or hard of hearing; ensuring accessibility of facilities, equipment, services, and programs; and basic training of providers, medical groups, and staff.
5. *Quality standards and monitoring of civil rights standards should be developed with people with disabilities in mind.* States' definition of standards and monitoring should look to examples from other states' experiences; take advantage of care coordination to increase efficiency and effectiveness; and be developed and informed by all stakeholders, especially beneficiaries with disabilities.⁶³
6. *Reimbursement or capitation rates or both must cover the real costs of providing medical care to people with disabilities and chronic health conditions.* Rates must reflect the fact that serving some individuals with disabilities takes more time and resources than serving other population groups and that high initial investment is required to produce long-term savings. The MCO must not have financial arrangements that create an incentive to withhold medically necessary care.
7. *People with disabilities should be represented in groups developing models and contracts for managed care and development and implementation of state oversight.* Representatives should include beneficiaries with disabilities, representatives of children with developmental and other disabilities, and qualified advocates with disabilities. These representatives should help develop standards for appropriate services for these population groups and advise state agencies on innovative, cost-effective approaches to improving care for them. Diverse disabilities should be represented in the oversight group.
8. *All health plans that accept Medicaid should provide medically necessary care—services, equipment, and pharmaceutical supplies.* The contractual definition of “medically necessary care” must assure the provision of all items and services needed to maximize the

⁶²Americans with Disabilities Act of 1990 (Title II), Pub. L. No. 101-336, 42 U.S.C. §§ 12131–12134; Rehabilitation Act of 1973, Pub. L. No. 93-112, tit. V, § 504, 29 U.S.C. § 794.

⁶³For more discussion of the quality information that should be publicly available, see Jane Perkins, Q & A: Assuring Accountability and Stewardship in Medicaid Managed Care: Public Reporting Requirements for States and MCOs (2007), www.healthlaw.org/library.cfm?fa=download&resourceID=104754&print.

patient's functional ability and promote and preserve the patient's ability to live independently in the community.



Millions of Medicaid beneficiaries are receiving care through managed care entities. All signs indicate that this trend will continue and likely accelerate. Medicaid beneficiaries with disabilities face particular challenges when enrolled in managed care. At the same time, managed care presents opportunities to improve

and streamline care for people with disabilities. Advocates should closely monitor developments in their states to guard against risks posed by managed care but remain open to opportunities to increase community integration and the quality of care, and life, for this population.

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