

# Reforming Medicaid and Vulnerable People

**Arnold Birenbaum**

The Rose F. Kennedy University Center for Excellence in Developmental Disabilities  
Department of Pediatrics  
Albert Einstein College of Medicine  
Bronx, New York 10461

**M**edicaid, the federal-state financed program that assists people to gain access to health services when they cannot afford them, has been in the news of late. Unfortunately the news is disquieting for people who count on this program for health care and rehabilitation services. Change is not always the friend of vulnerable people, and in this instance, it can be downright disruptive when it comes to accessing services. Because they are not well organized, people with Medicaid coverage do not have political clout, even though more people are covered by Medicaid than Medicare (e.g., the public insurance program for almost all people over the age of 65 and some people with disabilities). New Bush administration proposals and ongoing practices could be particularly harsh for people with disabilities.

First, on February 3<sup>rd</sup>, 2003, Tommy Thompson, Secretary of the United States Department of Health and Human Services (HHS) and the former governor of Wisconsin, made a bold proposal: allow states to generate any waivers they wish, without prior federal approval. And funding for Medicaid would be split into two pots—acute and long-term care. On February 20<sup>th</sup>, the HHS Secretary sought the approval of the National Governors Association for this plan, one that would give states options in how they spend their proposed block grants. When the former Wisconsin governor compared these reforms to Temporary Assistance to Needy Families legislation (TANF), I listened carefully and thought about how his proposal will impact children with special health care needs and adults with disabilities.

Determining the intended and unintended consequences of major health care reforms is a central task in any responsible health policy analysis. On the heels of Tommy Thompson's speech, Ted Halstead, president of the New America Foundation, in an Op-Ed piece in *The New York Times* (2003), called for guaranteed universal coverage, which, he claims, will eliminate the need for a separate Medicaid system for the very poor. Halstead was well intentioned but misinformed. Medicaid is more than a safety net for poor people; it is a complex program that is extremely valuable for those who have long-term health and social support needs.

Medicaid has to be handled with care. Many of the services it pays for are special. It's the health care and social support system of such fictitious Americans as grandma Bessie in the nursing home, uncle Bill with a history of

mental illness who lives in a half-way house, and cousin May with severe chronic childhood illness and a developmental disability. These homey examples are not meant to make readers reach for their box of tissues, but to point out how Medicaid has evolved into a mix of health, social, and psychoeducational programs, each tailored to a specific client population.

Medicaid, from its start, has offered states the choice of furnishing an impressive range of optional services to clients. It has also subscribed to definitions of medical necessity that are far broader than those found in commercial insurance policies. Optional services and definitions of medical necessity complement each other; they encourage medical providers to prescribe speech, physical, and occupational therapies, even when cure or recovery are not possible.

The Social Security Act, which authorizes the Medicare and Medicaid programs, allows the Secretary of the Department of HHS to waive the Department's rules and regulations, permitting states to make applications to innovate. Waivers are especially important in encouraging children and adults with serious chronic illnesses or disabilities to lead normal lives, including living in the community and with family. Consider the Katie Beckett Waiver program, conceived when Julie Beckett, the mother of a three-and-a-half year old with viral encephalitis, discovered that Medicaid would pay thousands of dollars to support her daughter Katie in a hospital, but would not pay for medical services and equipment (e.g., a portable respirator that would allow Katie to live at home). Katie was eligible for medical assistance because the family had spent most of their assets to pay for her extraordinary medical bills. The state of Iowa would not pay Katie's bill, a smaller expense than hospital care, if she returned home, so Julie petitioned President Ronald Reagan to waive the Medicaid rules to permit Katie and 300,000 others to have home care and remain with her family (Roberts and Considine, 1997).

Established in 1981 by the HHS Secretary, the "Katie Beckett Waiver," as it became known, is an override on Department regulations. It permits states to use Medicaid funds to assist children with special health care needs to avoid hospitalization and be with their families at home.

The story continues to validate the idea that consumers can be the best advocates. Julie Beckett not only made

## Reforming Medicaid and Vulnerable People

Medicaid more flexible, she later founded a voluntary association made up of parents just like herself. In 1998-1999, a national survey was conducted by Brandeis University and this advocacy organization, Family Voices (2003), with funding by the David and Lucille Packard Foundation. In this study, 2220 families of children with special health care needs reported that their satisfaction with care and services paid for by Medicaid was greater than the care paid for by private insurance.

Thus, Medicaid plays an essential role in assisting families of children with special health care needs. This impact goes far beyond keeping American children healthy. Children who have access to skilled and experienced specialists; physical, occupational, and speech therapy; and other optional services miss fewer school days and are less subject to hospitalization.

Putting a human face on health care does not stop with children. The Home and Community Based Waiver Program (HCBW), made law as a part of the Omnibus Budget Reconciliation Act (1981), was created as a way to contain increasing costs of institutional care paid out of federal revenues. The funding authority for this program came from amendments to the Social Security Act, wherein states could receive Medicaid matching funds to provide home and community-based services to individuals who otherwise would receive care in a nursing home. What is truly unique about this program was the authorization to states to pay for clinically appropriate non-medical services, including care coordination, habilitation services (i.e., occupational, physical, and speech therapies), homemaker services, personal care, and adult day care.

The original purpose of the HCBW Program was to dampen the demand for institutional care by making other, more affordable community-based services available to low-income individuals with chronic disabilities and illnesses. Under the HCBW, the United States Department of HHS allows states to finance community services through Medicaid for people with developmental disabilities who would otherwise be in Intermediate Care Facilities (ICF/MR). By 1995, all 50 states were participating in the HCBW.

The HCBW initially accounted for only a small percentage of total expenditure on community services in the United States, but it grew rapidly during the 1980s, making it, by 1994, the largest source of federal funds for community services. The program establishes individualized service options and family supports, administered by the state mental retardation and developmental disabilities agency through direct payments to service providers. Included among these services are: habilitation services, respite care, family counseling, equipment to promote adaptation or safety, architectural adaptation of the home, in-home training, education, behavior management, and recreational services.

In my opinion, optional services and waiver programs represent the impressive flexibility already built into Medicaid. The Bush administration is throwing the states facing substantial deficits a lifeline without having to appropriate additional funds to assist them. At the National Governor's Conference on February 24<sup>th</sup>, 2003, President Bush told both parties that no further assistance for their enormous deficits were going to be fueled by the federal treasury. Moreover, this new move toward state autonomy will only lead down the path of allowing the states to avoid being out of compliance with their established obligations when they start restricting access to optional services and waiver programs. No longer will state departments of health be able to identify an appropriate benefit for a patient population with expensive medical bills or long-term intervention requirements including cost-saving care coordination services and Medicaid. This safety valve encourages providers to do the necessary interventions for the medically needy and the disabled. Do we dare risk further destabilization of our health care system by downsizing or eliminating an extremely important set of services and programs? Maintaining adequate funding of Medicaid, two-thirds of which goes to pay for optional services, is especially important for vulnerable populations.

A second way Medicaid has made the news recently is on the front page of the business section of *The New York Times* (Freudenheim, 2003). Medical business reporter Milt Freudenheim, on February 19<sup>th</sup>, found a trend toward privatization of Medicaid services via for-profit managed care companies. These companies, with the encouragement of the Bush administration, have skimmed off the most frequent types of Medicaid recipients, healthy children and their mothers. These clients need very little in the way of services. Most of the costs of Medicaid go to long-term care services for people with disabilities, the elderly, and those with serious chronic illnesses. Many of these procedures are found in the optional services section of this public insurance program, which states may pay for or decline to support.

Managed care companies supply preventive health services to this relatively low-cost population and avoid elderly and disabled Medicaid recipients, the far more extensive users of services. Profit making depends on selection and avoiding adverse risks. Once in Medicaid managed care plans, those who are seriously ill are sometimes denied authorization for services or, when they receive services, their providers find that it is tough to get paid.

Do we need to further divide the Medicaid service system and the populations that it serves? A cost-driven health-care payment system will lead to denials of access for the categorically needy (e.g., TANF recipients) and the medically needy (i.e., people with medical

## Reforming Medicaid and Vulnerable People

expenses that overrun their assets and incomes). Some providers, particularly hospitals and academic medical centers, are already unwilling to contract with Medicaid managed care plans that refuse to pay or delay payment for several months.

All of these changes, proposed or ongoing, today rest on a shaky platform of state debt. The states address the issue of loss of tax revenue by cutting capitation payments to managed care plans and providers in the fee-for-service parts of Medicaid or limiting eligibility to the poorest part of the population. Under funding will produce penalties for consumers as providers leave plans. Moreover, patients may either seek more accommodating plans or will follow their doctors to other plans. This kind of "churning" has consequences. It will mean that the combined service advantages of managed care (i.e., intensive care coordination) and Medicaid (i.e., removal of the financial barriers to access to care) will be unrealized. They will be eclipsed by the need for consumers to learn about new rules and regulations, once again, of a new managed care plan, and providers will be compelled to make new assessments of what patients require in the way of care.

Since its inception in 1966, Medicaid has worked as an acute care safety net for the categorically needy and taken on the characteristics of a wrap-around patch-work quilt for people with long-term care needs. It has evolved into 50 different state programs. The level of generosity of each program varies, since the income cutoff levels, the extent to which optional services are offered, and the payment schedules for physicians, hospitals, and other providers varies from state-to-state. It does not need to be fixed through block granting and creating more health plans. It needs a powerful infusion of funding to attract more quality providers and an environment that encourages the continuation of the

availability of long-term care services to populations that depend on them. It may also require additional funds from the federal government to extend it to families with children with special health care needs, who cannot afford to purchase private health insurance or who are regarded as adverse risks in the insurance marketplace. This new entitlement is already part of proposed omnibus federal health-care legislation, a well-intentioned Senate bill (S.10) that is unlikely to be signed into law.

In other words, Medicaid is more than a safety net for those who live in extreme poverty. It is a medical and social program that has grown incrementally according to need. Protecting Medicaid today is as important as protecting Medicare. Currently, it is in danger of being divided by block granting and privatization. So long as the United States fails to introduce universal coverage with appropriate benefits for children with special health care needs, the elderly, and people with disabilities, Medicaid represents federal and state creativity. Do not let the President's anti-government, pro-business public relations campaigns make you believe that less is more.

### REFERENCES

- Freudenheim, M. (2003) Some Concerns Thrive on Medicaid. *The New York Times*. February 19, 2003:B1.
- Halstead, T. (2003) To guarantee universal coverage, require it. *The New York Times*. January 30, 2003:A27.
- Public Law 97-35, section 2176 (1981) United States Codes.
- Family Voices (2003) The importance of public insurance/Medicaid coverage for children with special health care needs. Retrieved January, 2003, <http://www.familyvoices.org.html>.
- Roberts, B.S. and Considine, B.G. (1997) Public policy advocacy. In: *Mosby's Resource Guide to Children with Disabilities and Chronic Illness*. Wallace, H. M., Biehl, R.F., MacQueen, J.C., and Blackman, J.A. (eds.), Mosby-Year Book, St. Louis. pp.162-171.

## EJBM Commentary

Commentary presents an author's opinion, explanation, or criticism of a specific topic within science, medicine, etc. Commentary can be submitted by electronic mail ([ejbm@aecom.yu.edu](mailto:ejbm@aecom.yu.edu)) or regular mail (1300 Morris Park Avenue; Forchheimer Building, Room 306; Bronx, New York 10461). Receipt of Commentary is acknowledged. Commentary is not peer reviewed and represents the viewpoint of the author on a particular issue or topic. Commentary is edited for space and clarity.