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**Don't Stint on Medicaid in Order to Cover All New Yorkers**

I commend Governor Spitzer for seeking to furnish health insurance coverage to all New Yorkers. I have applauded his effort to redirect Medicaid back to its mission of caring for the poor and medically needy, despite the flack I have taken from colleagues at academic medical centers. Moreover, I have also urged the expansion of SCHIP to cover all children in the state. And I have done my applauding and urging with two op-ed pieces in the Journal-News, a Westchester-Rockland Counties Gannett daily.

Current State efforts to create universal coverage need to fully address the *adequacy* issue related to coverage. The opportunity to create universal coverage comes with threats to the adequacy of coverage for people with disabilities, in a way similar to dangers presented during the explosive growth of managed care in the 1990s. Today, savings via Medicaid managed care may help to create access for the uninsured. But managed care, largely primary care expansion, is not a panacea for meeting the needs of people with serious chronic illnesses and disabilities.

Fee-for-service specialty care via Medicaid is the most important source of health care coverage for people with serious disabilities. Simultaneously, Medicaid is a budget-cutters dream because it is such a large part of NYS and Federal spending. Unchanged

rates at free standing ambulatory care centers going back to 1996, as stated by Deborah Bachrach, New York State Commissioner for the Office of Health Insurance and Medicaid Director, at a recent symposium at the New York Academy of Medicine, deserve revisiting and resetting to maintain services. Medicaid rates for ambulatory visits at these facilities have been frozen for 12 years. Freestanding clinics, especially those licensed to provide limited specialty services or to serve special needs populations, are particularly vulnerable and could become an endangered species for a number of reasons: (1) the services they provide are manpower intensive, often requiring costly multidisciplinary multi-system assessments and a great deal of case management across service systems; (2) they cannot be cross-funded by profit centers in hospitals; and,(3) because they often do not provide routine primary care, but rather coordinate care with primary care clinics and private physicians, they are not afforded the federal reimbursement protections available to “federally qualified health centers” nor have they been eligible to receive funding from the State Department of Health’s “charity care distribution pool”.

Losing these clinics is not the way to deal with the multiple consequences of severe disability for the individual and for family members. Some of the secondary disabilities encountered by families relate to the mental health of children, a neglected area in our society. A child who needs this intervention rarely gets it because of a shortage of community programs, long waiting lists, and a lack of skilled therapists. A substantial number of children with disabilities who need medical rehabilitation and assistive technology have limited access to them, whether in fee-for-service or through

managed care plans. And the most in need, either because of severity of disability, poor health, or low income, have the most to lose if these programs are eliminated.

Medicaid is often called the gold standard by professionals in the field of disability. It makes services, assistive devices for communication and mobility and prosthetics available to people with severe disabilities because optional benefits exceed what is available under private insurance. NYS has recognized that rehabilitation interventions are required, even when costly. However, incrementally building up access to these services, equipment and supplies gets noticed by state officials. As noted, eligible people with disabilities are often the most frequent and expensive users of Medicaid. Consequently, efforts to create and sustain supports for people with severe disabilities are often undermined by budgetary constraints.

It is not only people with disabilities who are impacted by budget constraints. States can restrain spending by lowering income eligibility cut-offs, reduce coverage of optional benefits, or refuse to raise the rates for procedures so that payouts to physicians are limited. This last mechanism for cost containment is a key issue in NYS. When payments are low, doctors, even participants in Medicaid managed care plans, will limit the number of Medicaid patients they will see, or will refuse to add new patients to their rosters. *Wall Street Journal* reporter, Vanessa Fuhrmans, found that national trends toward low payment limits access for Medicaid patients, especially when it comes to the availability of specialists (Fuhrmans, July 19<sup>th</sup>, 2007). Her article, “Locked Out—Note to Medicaid Patients: The Doctor Won’t See You Now; As Program Cuts Fees, MDS Drop Out; Hurdle for Expansion of Care,” suggests that many states pay so poorly that they

cannot guarantee the availability of medical care, as required by the original Medicaid legislation. This trend is equivalent to silent rationing.

### **Pay Attention to the Shrinking of the Service System**

While low payment rates are chasing specialists away from Medicaid patients, if they choose to see a limited number of Medicaid-eligible patients, they are able to offset their pro bono services with payments from other patients. When Medicaid is the primary source of revenues, the situation is not so easy to remedy. Direct local observations acquired at a multi-discipline diagnostic and treatment center that serves mostly children with developmental disabilities in the Bronx, the poorest county in NYS, will serve as eyewitness reporting regarding how federal and state efforts to economize are hurting poor families with members who have disabilities. First, during the past 14 years, I have noted many accomplishments at the Bronx-based Children's Evaluation and Rehabilitation Center (CERC), a nationally, regionally, and locally esteemed program, and the clinical arm of the University Center for Excellence in Developmental Disabilities. Many children with developmental disabilities improve their capacity to learn following speech, physical, and occupational therapy, or the acquisition of hearing aids and glasses. Others are prevented from deteriorating and avoid progressive loss of function.

Second, CERC also furnishes braces, appliances, and other aids to children with physical as well as intellectual disabilities, in partnership with experienced vendors. I have also observed, as have readers of New York's press, that pleas for Medicaid-funded durable medical equipment (DME) has gone unanswered in New York City for about 3 years. The New York State Department of Health took the position that many of the

requests for equipment are medically unnecessary. There is a substantial price to be paid for limiting authorizations for DME. Without maintaining mobility enhancements and appropriate seating, children with disabilities cannot develop intellectually and socially. They cannot be fully involved in their family's daily lives; in some cases, they will not be able to attend school; in others, to maintain the appropriate upright position for classroom learning; and participation in community life will be limited.

Saving money by limiting Medicaid payments for DME has unintended consequences and spills over in other areas of public support. When equipment isn't maintained, the cost of municipal services goes up. One CERC patient, an adult, could not get to the elevator in his building to get to the street because the mechanized wheel chair he used was in need of repair. A call to 911 sent emergency medical assistance as well as police officers. Of course, some of the cost of this help was paid for by Medicaid, a price well in excess of the proposed repair. Police services come out of a different budget. In the end, the taxpayer pays in both ways.

Self-advocates and family members were able to spark a NYS Assembly hearing concerning the NYS DOH's pace in handling of Medicaid durable medical equipment claims. Conducted during the summer, 2006, the authors of this report asserted that the Department has been "systematically depriving poor people with severe disabilities—many of them children—of wheelchairs and other 'durable medical equipment' they need to reduce their pain, preserve their health, and enable them to live more productive lives" ("Delaying Necessities, Denying Needs", 2006, p.4). The authors go on to say that the savings generated by the NYS DOH are short term and result in long-term increased costs while failing to comply with state law.

## **Maintain Capacity: Avoid Limiting Independence and Community**

### **Adaptation of People with Disabilities**

In sum, slowing down the replacement or maintenance process is hardly going to improve the independence and community adaptation of wheel-chair users or those who require leg braces. Access to adequately functioning DME is a medical necessity. I note today that the NYS DOH is slowly, very slowly, coming around to recognize this policy.

Another form of savings for the state also impacts directly on the lives of people with disabilities as well as threatening service capacity. In order to provide specialized interdisciplinary diagnostic, health related treatment and dental services to children and adults with developmental delays and disabilities, and be eligible for public funding CERC is licensed by both the New York State Department of Health (DOH) and Office of Mental Retardation and Developmental Disabilities (OMRDD) as a Specialty Clinic. Such facilities were initially established to provide for the early diagnosis and therapeutic care for children, and later adults, involved with developmental disabilities. As stated earlier, these clients require a coordinated multidisciplinary approach to care, that is time consuming and costly, and in many instances not available in other venues. Most such services should be “carved out” from Medicaid managed care, but coordinated with any managed care entity providing basic medical services

Those seen at CERC and other similar Clinics are a professionally time-consuming population, unwelcome in private practice settings. These facilities not only diagnose, but are intended to create access to ongoing therapy and to maintain or improve current levels of functioning for people with developmental disabilities. CERC is running a deficit because revenues have not kept pace with the cost of operations. This is not due

to mismanagement. Article 474 of a 1996 New York State law froze Medicaid reimbursement for all Free standing Article 28 Clinics 12 years ago, not taking into account routine increases in salaries, costs of health insurance, Y2K and HIPAA mandated implementations, increasing technology costs and escalating fees for medical malpractice. Despite promoting greater efficiencies at CERC, flat rates are not the way to counteract years of inflationary costs.

Remedies to this dire financial situation have been attempted. But downsizing through past and even future reductions in professional staff size will not stave off service reductions or the massive downsizing of CERC. In addition, shrinking the professional staff means more time between appointments, making it more difficult for people with developmental disabilities to access the services that help them optimize their capacity to learn in school, participate in family and community life, or compete in the work force.

This situation represents a policy retreat from the 40 year-old social compact that generated Medicaid. Moreover, recent supposed federal reforms of Medicaid (DRA) put greater restraints on service utilization by people who need to maintain access to care. Co-pays reduce use of necessary services, including medications, as well as unnecessary services. A low-income person with epilepsy who stops taking anti-seizure medication in order to avoid co-pays may also invite a seizure and a fall, and, as a result, may be hospitalized with various fractures. This is hardly a constructive way to offset costs. It is a way to fill costly hospital beds.

Maintaining capacity and access is the cost-effective way to assist low-income people with disabilities. Free Standing Specialty Clinics need to receive regular Medicaid rate adjustments that will allow them to continue their mission—addressing the needs of

this vulnerable population. New York State Medicaid must also ensure that their payment systems, for specialty clinical services and associated transportation, can identify and reimburse providers for Medicaid managed care “carved out” services that are not part of traditional capitation rates, and ensure service availability for special needs children and adults. A small, one-shot supplement--targeted for recruitment and retention—was permitted in Governor Pataki’s last budget. It was scheduled for termination, but was reinstated as a result of some disability community-based lobbying efforts. Clinic administrators have indicated that it is clearly not enough to sustain their programs. Without decisive restoration to a margin of financial health, CERC and similar facilities cannot continue their mission and their patients will not optimize their independence and productivity. Expanding coverage should not be at the expense of Medicaid’s important functions in the lives of people with disabilities. Do no harm in extending coverage: Adequacy of benefits and service capacity must be maintained.