

Testimony of Linda Ostreicher

New Yorkers for Accessible Health Coverage
Partnership for Coverage Public Hearing, October 30, 2007

I am here today representing New Yorkers for Accessible Health Coverage (NYFAHC), which is a coalition of over 50 organizations representing people with serious, chronic illnesses and disabilities. I'm also representing my employer, the Center for Independence of the Disabled, New York (CIDNY), which is a member of NYFAHC.

Today I would like to focus on aspects of health coverage which are particularly crucial to people living with serious, chronic illnesses and disabilities. They are uninsured as often as non-disabled people—they just need coverage more.

Mr. Jones* , a CIDNY consumer in his 40's, was paralyzed in an accident years ago. He isn't poor enough to get Medicaid—he has \$180,000 from a settlement related to the accident that paralyzed him. However, his income, at under \$17,000 a year, is too low to pay his bills, so he is spending his savings every month.

Mr. Jones has Medicare, but it doesn't cover his \$400 monthly co-payment for medical supplies for his urinary catheter. Medicare did not housekeeping he needed when he broke his hip, The prescription drugs Mr. Jones needs total about \$14,000 a year. Medicare Part D doesn't cover all of that, either—his share is several thousand dollars.

He's all right now because CIDNY staff helped him to get Medicaid, which has become the gold standard of public health coverage.

Family Health Plus (FHP) would not have been as good as Medicaid for Mr. Jones—it wouldn't pay for the \$2,000 in medical supplies he needs each month.

Healthy New York is even more limited than Family Health Plus. It wouldn't have provided the wheelchair Mr. Jones needs because his legs are paralyzed; nor would it have covered his medical supplies. Healthy New York recently added physical therapy to its benefit package, but not occupational therapy, which Mr. Jones needed after his hip fracture, to learn how to put on shoes while his leg was in a cast.

For people with disabilities, "bare bones" coverage is a disaster. We are major users of rehabilitation, home care, durable medical equipment, and prescription drugs.

CIDNY and NYFAHC have been trying for many years to get the Elderly Pharmaceutical Insurance Coverage (EPIC) program expanded to those Medicare enrollees who are under 65. The Medicare Part D benefit helps younger Medicare enrollees, but it has large holes in it that people with disabilities are no more able to afford than elderly people. We expect any health coverage reform package proposed by the Governor to include this obvious step.

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Another consumer, Mrs. Brown*, is a 39-year-old woman who developed myelitis, which paralyzed both of her legs. Her only coverage was her husband's private insurance from his job, which didn't include home care or the wheelchair she needed. He had considerable savings, which he was rapidly spending for the 24-hour home care she needed.

Medicaid was not an option for reasons I won't take time to detail. If she had been on Medicaid, all her needed services would have been covered.

Mrs. Brown hadn't worked long enough to get Medicare, but even if she had, the wait time to receive benefits would have been a disaster. There is a 24-month wait for Medicare from the day you start getting SSDI benefits. So, Mrs. Brown would not have had received coverage during the time when she most needed rehabilitation, medical care, and mental health services to deal with the changes in her life caused by suddenly becoming disabled.

The only public medical insurance that provides ongoing 24-hour home care if you need it is Medicaid—not Medicare, Family Health Plus, or Healthy New York. And, as with Mr. Jones, Healthy New York would not have covered a wheelchair or mental health care.

Fortunately for the couple, Mr. Brown is a Canadian citizen, and the last time we heard, he was thinking of moving his family back to Canada, solely because of the health coverage.

Finally, the complexity of our patchwork health system imposes enormous costs on the consumer. When people are sick or injured, the last thing they need is to have to fight with a bureaucracy to find out who covers what kinds of care they need.

People with mental illness can be extremely discouraged or distrustful of medical care, and small barriers can prevent them from getting essential care, with terrible consequences to themselves and others.

Similarly, people who have speech or hearing impairments making it hard to use the phone, can find it impossible to communicate with health plans, let alone resolve coverage problems.

For every consumer CIDNY helps to get the health coverage to which they are entitled, or to convince medical providers to reduce their bills, there are hundreds who don't find their way to us. They go without care until their conditions get much worse, risking the loss of their ability to work or live independently, or even the loss of their lives.

Like many of the other speakers here today, CIDNY and NYFAHC call for universal, comprehensive, accessible, affordable, and high-quality health coverage in New York State.

* Names have been changed to protect the individuals' privacy.