

Center for Independence of the Disabled, NY

Testimony by Greg Otten
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Thank you for giving me the opportunity to testify today. My name is Greg Otten. I am a Direct Services Supervisor at Center for Independence of the Disabled in New York (CIDNY). CIDNY is a non-profit community-based organization and is part of the Independent Living Centers movement -- a national network of grassroots and community-based organizations that enhance opportunities for all people with disabilities to direct their own lives. CIDNY's goal is to ensure full integration, independence and equal opportunity for all people with disabilities by removing barriers to the social, economic, cultural and civic life of the community.

I am speaking today from the perspective of a health benefits counselor. For the past six years I have helped disabled consumers to navigate the mind-boggling intricacies of our health coverage system. I have been able to help many consumers obtain or maintain coverage, but there are gaping holes in the system. Simply put, many consumers cannot afford private health insurance or qualify for public health insurance. I will lead you through some of these treacherous waters and show you why navigating the system is so incredibly frustrating for our consumers and for us as advocates.

Frankly, there is no question that we all need easy access to comprehensive and medically appropriate health care. In particular, people with disabilities or chronic health conditions need access to a wide range of medical services. But universal healthcare is an issue for everyone: serious illness or disability could face anyone at any time, including all of you and your loved ones.

Let me describe some of the ways people get health coverage in New York.

Commercial Health Insurance

Some of us have comprehensive health insurance through our jobs. Other New Yorkers without employer-based coverage may purchase comprehensive "direct pay" individual health insurance. New York State is progressive in that such coverage is guaranteed available to everyone at the same cost, regardless of health status. We must not return to earlier days when people were excluded from health insurance or were charged higher premiums based on pre-existing health conditions.

The problem here is not access, but affordability. Direct pay coverage is exorbitantly expensive: premiums for a single person in Manhattan currently range from \$502 to \$1,556 per month. Family coverage costs \$1,954 to \$4,073 per month. These rates often increase over 10% annually. Most New Yorkers cannot afford these premiums. Premiums are high because people who purchase this coverage tend to be sicker, so insurers have higher claims costs. CIDNY

believes that the direct pay market should either be merged with larger markets (such as small businesses), or the costs of sicker or disabled consumers should be more fully covered by broad-based financing sources, like tax revenues.

Healthy New York for the Healthy Only

While I am on the topic of commercial health insurance, I want to mention another type of product called "Healthy New York." Healthy New York is available to certain low-and middle-income New Yorkers who have no other access to coverage. Individual premiums in Manhattan currently range from \$224 to \$301 per month. I like the name Healthy New York because this coverage is appropriate only for very "healthy" people, and only for as long as they remain healthy. The name is all I like about Healthy New York; its coverage package is totally inadequate for people with disabilities and chronic health conditions.

Healthy New York's website lists certain exclusions from coverage: no coverage for mental health services (including treatment and medication for ADHD, depression, and anxiety), no alcohol and substance abuse treatment, no chiropractic coverage, no hospice care, no ambulance, no dental care, no vision care, no coverage of durable medical equipment (like wheelchairs), and a \$3,000 annual limit on prescription drug costs. These excluded services are ones needed most by people with disabilities and chronic conditions. For example, a person with Healthy New York who becomes unable to walk would have to pay the full cost of a wheelchair. A person who comes down with acute appendicitis in the middle of the night would have to pay the full cost of ambulance transportation to the emergency room. A person taking expensive prescription drugs would have to pay as much as tens of thousands of dollars annually for conditions like cancer, HIV, chronic hepatitis, and many others. A number of universal health coverage proposals incorporate Healthy New York as a coverage option. CIDNY believes that Healthy New York coverage is totally inadequate and should not be part of any universal health coverage proposal.

Public Health Insurance Gaps

What coverage options are available for people who have no employer-based coverage and who cannot afford direct pay individual coverage? They may, and I stress, may, be eligible for one of the public health insurance programs: for example, Medicare, Medicaid, Family Health Plus, and Child Health Plus. Eligibility rules for these public programs are nightmarishly complex, and not everyone qualifies.

Working Poor = Poor Coverage

Let's consider CIDNY's consumer, John. He freelances as an artist and earns about \$2,000 a month. As it is, he barely makes ends meet and cannot afford health insurance. Due to a life-threatening cardiac arrhythmia, he recently needed an emergency implantation of a defibrillator. This particular consumer came to me before he received any bills, but he was told that his hospital bill alone would come to about \$130,000. Ancillary medical providers (for example, the anesthesiologist) will be sending him a number of additional bills. John will never

be able to pay off these bills. Although he has a chronic heart condition, he works and earns too much to qualify for Medicaid or Family Health Plus. He cannot afford commercial direct pay insurance, and Healthy New York is inappropriate for him. What can he do?

A new charity care law will require the hospital to reduce his bill, but John's balance will still be prohibitive. The hospital must also work out a monthly payment plan, but it can still insist he pay as much as 10% of his income each month. If John was struggling financially before the hospitalization, an additional 10% payment will certainly be too much for him to handle now. Furthermore, the additional ancillary providers are not bound by the charity care law and can insist on full payment now. John is being as responsible and pro-active as he can, but he's understandably very anxious.

Frightened by Illness, Frozen by Debt

We see other consumers who are so frightened by medical debt that they cannot even open the bills they receive in the mail. Ignored bills are turned over to collection agencies, and eventually consumers' bank accounts are frozen, leaving them without access to their money. Once, a consumer named Jim walked in on a Friday at 4:45 p.m. His bank account just had been frozen, and he had no cash on hand. He was referred to debtor/creditor attorneys who eventually helped him sort things out, but he was in a precarious situation that weekend without any cash.

People are usually responsible and want to do the right thing and pay their bills. But uninsured consumers frequently become overwhelmed by the magnitude of their medical bills. They feel humiliated and ashamed when they get bills they can't pay. I try to reassure them that it's not their fault. They feel cheated and angered by a system that takes their tax revenues and then leaves them in the lurch when they most need help.

Consumers Who are Unable to Work

John, the consumer with the heart condition, was an example of someone who works, has no employer-based insurance, can't afford commercial direct pay insurance, but earns too much to qualify for public insurance. At CIDNY, of course, we also see many consumers whose disabilities are serious enough that they cannot work. These consumers frequently receive Social Security disability benefits. Eligibility for public health insurance programs is more generous for disabled than for non-disabled individuals. However, even totally disabled consumers often have difficulty getting adequate healthcare coverage.

Waiting for Coverage That Impoverishes Pocketbooks and Health

Let's consider consumers under age 65 who apply for Social Security Disability benefits when they stop working. When they apply for Social Security Disability, they must wait five months before benefits start. They struggle to meet basic living costs during that time. They cannot afford COBRA premiums (continuing employer-based health coverage for people who leave employment). Once

disability income benefits do start, consumers still must wait an additional two years before Medicare starts. And once they finally get Medicare, they find that Medicare does not cover all of the medical services they need, for example, custodial nursing home care and home care, routine physicals, routine eye examinations and eyeglasses, hearing examinations and hearing aids, dental care, routine foot care, most immunizations, and half the cost of psychotherapy. Many consumers have difficulty affording Medicare premiums (\$96.40/month in 2008), the annual deductible (\$135 in 2008), and the 20% coinsurance on doctor bills.

How, then, in today's world can disabled individuals obtain the comprehensive health coverage they need? If their monthly income is low enough (\$700 for an individual, \$900 for a married couple), and they are citizens or legal immigrants, they may qualify for Medicaid, which covers many of the services that Medicare doesn't cover. If their incomes are higher, they can "spend down" to Medicaid eligibility levels. For example, someone with \$800 countable monthly income can get Medicaid each month, but only after incurring \$100 in medical bills. Medicaid spenddown is notoriously difficult to navigate, particularly for consumers with disabilities. Think about mobility-impaired consumers who cannot get to a Medicaid office to show medical bills and meet their spenddown, or cognitively-impaired consumers who have trouble understanding any correspondence they receive from Medicaid. And what about consumers who simply cannot afford to pay bills equaling the spenddown amount? Many individuals on Medicaid spenddown are unable to activate their Medicaid coverage for these reasons.

Navigating the Complex Medicaid/Medicare Systems

A CIDNY's benefits counselor currently works with a married couple, Steve and Marian. They are both homebound. Both receive Social Security Disability and Medicare, but neither can get Medicaid because of the spenddown problem I described. Many of their doctors refuse to see them unless they pay Medicare's 20% coinsurance up front. This couple has no access to needed services that are covered by Medicaid but not by Medicare, such as homecare, dental care, and transportation to medical appointments.

Disabled consumers who are lucky enough to qualify for full Medicaid do receive comprehensive benefits, but even they face myriad problems. Previously, all Medicaid enrollees were allowed to visit any Medicaid provider. Now, more and more people are required to join managed care plans, and they are restricted to doctors who accept their new plan. Choosing an appropriate plan is problematic for many consumers with disabilities, particularly those who see a large number of specialists. Finding one plan accepted by all specialists can be difficult if not impossible, so some consumers must find new doctors who will accept their new managed care plan.

Certain consumers can be exempted from managed care, but getting the exemption requires that the consumer and physician complete an exemption form – more red tape. Most recently, the severely and persistently mentally ill lost their exempt status. Many of those least able to navigate the red tape must select

plans or request exemptions. Those who fail to do so are randomly auto-assigned to a plan without regard to whether their doctors accept that plan. We frequently see consumers who learn about managed care only when they go to a doctor visit and are told their Medicaid card does not work. They have been auto-assigned to a plan not accepted by their doctor.

In fairness, I should note that we do have a sort of safety net for people who are un- or underinsured. People who meet certain income guidelines (significantly higher than Medicaid's) qualify for sliding-fee-scale programs at Federally Qualified Health Clinics and at Health & Hospitals Corporation hospitals. The problem is that most people don't know about these programs. And sometimes, when I refer consumers to the public hospitals, they don't follow through because they are intimidated by the bureaucracy and the long waits at these facilities. Our consumers want and deserve a choice of doctors and do not want to be restricted to one particular clinic or hospital.

Informed Choice?

I can't finish my description of our healthcare system without mentioning the new Medicare Part D drug benefit, one of the most complex benefits known to mankind. Currently, there are about 55 standalone drug plans to choose from in New York City, plus about 45 Medicare HMO's with a prescription coverage component. Each of these plans has a different formulary, or list of covered drugs.

To make an informed plan choice, consumers really need to find a computer and use Medicare's PlanFinder. They have to enter the name, dosage, and frequency for each of their medications to find out which plans cover which drugs. They have to check a separate web page to find out which covered drugs are subject to prior authorization restrictions. Many disabled consumers cannot afford computers, do not know how to use them, or are physically or cognitively unable to use them. Advice given by Medicare over the phone is frequently erroneous or incomplete, so consumers rely on our help to select the most appropriate drug plan. Medicare Part D formularies are more restrictive than those of commercial insurers, and consumers are frequently prescribed non-covered drugs. They walk into their pharmacy, only to be told that their plan won't cover their prescribed drug. Many doctors, overburdened with paperwork, refuse to assist consumers with Part D appeals. Instead, some doctors take the simplest route and prescribe alternative covered medications, which may be less effective or may actually be harmful.

Copays and Donut Holes Make Medicare Part D Out Of Reach

When drugs are covered, the out-of-pocket costs are exorbitant. Copays are high, and there is the notorious "donut hole." In 2008 Part D plans will provide some coverage for the first \$2,510 in total drug costs; consumers must then pay 100% of the next \$3,216.25 on their own (the donut hole), and only after consumers have spent \$4,050 of their own money will Medicare pick up 95% of the tab. People with chronic conditions frequently have such high drug costs that they do

"get through the donut hole" (if they can afford to), but they incur very high drug costs on the way.

It is true that consumers with lower incomes may pay lower Part D copays (\$1.05 - \$5.60 per drug). But consider the chronically ill consumer with limited income who takes a large number of drugs. If a consumer's total monthly income is \$800, and he/she takes 30 drugs at \$5.60 each, the monthly copays total \$168, an unacceptable 21% of total monthly income.

Thank you for taking this treacherous journey through the healthcare system with me today. I've tried to give you a sense of the complexity of health insurance coverage options in New York State. Navigating the system is challenging for any of us, but especially for people with disabilities who feel sick and fatigued, and who have difficulty comprehending written correspondence and dealing with phone trees. The fortunate ones can navigate the system on their own or find benefits counselors at agencies like CIDNY. But what about the people who cannot navigate the system or find their way to help? I worry about them.

Simple, Comprehensive, Accessible, and Affordable for Everyone

Partnership for Coverage is looking at several universal health coverage proposals. While CIDNY does not advocate any one proposal in particular, we would caution against proposals that merely move us from one sort of complexity to another, or proposals that incorporate barebones coverage like Healthy New York. We urgently advocate for a much simpler system that offers easy access to comprehensive, affordable coverage for everyone. Every single New Yorker deserves nothing less. As I said earlier, no one in this room or in this state can predict what future health problems lie ahead for us and our loved ones. On behalf of every New Yorker, I urge adoption of comprehensive, affordable, easily accessible, and universal health coverage.

Thank you very much.