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**Issues:**

- 1. Medicaid- the only option for the very sick**
- 2. Medicaid reimbursement, lack of providers**
- 3. Insurance plan denials of medication/treatment/disability**
- 4. Inadequate legal redress for insurance company denials**

**TESTIMONY**

I am a public interest attorney working with Nassau/Suffolk Law Services. Through a NYS Dept of Health grant, I provide free legal services to people with cancer in Nassau and Suffolk County. My clients must have a diagnosis of cancer to be eligible for legal services. My clients are some of the sickest and most in need of health care services in the county. Providing legal assistance to my clients has given me insight into what is good and what is not good about our healthcare insurance system in New York.

I would like to start by saying New York does a better job of caring for the sick than many other states. In NY, a person found to be sick or disabled is eligible for Medicaid. If there income is high, they will still receive Medicaid but will pay the overage or “spenddown”. Further, NY allows a shelter for this excess income of a disabled individual in a Supplemental Needs Trust thus allowing more of the disabled individual’s income to be used for non-medical needs.

This being said, the following real stories about individuals with cancer seem all the more disturbing. For example, we had a twenty-five year old client. He had been working at a pizza restaurant. He was enrolled in an insurance plan. Sadly, he was diagnosed with a grave, rare cancer. Shortly after this terrible diagnosis was made, his insurance carrier dropped his insurance because he failed to report a doctor’s visit for an episode of nausea some years prior. His only option for health insurance was Medicaid. He was approved for Medicaid and when the \$12,000 of out of pocket bills (from the only doctors in all of New York who would treat his rare condition) were submitted for reimbursement, Medicaid paid \$404.

Thus, as more and more individuals lose there private insurance through this practice of dropping the insured when they become catastrophically ill, Medicaid recipients are the sickest and presumably, the costliest citizens in New York. And while recipients are generally satisfied with Medicaid, providers are generally not. Reimbursements are low. In fact, a colleague midwife of mine practicing in rural Cayuga County tells me there is only one Medicaid provider in the entire county- making it impossible to refer patients with Medicaid needing additional treatment.

We have clients whose health is caught in the bureaucracy of the system. This is illustrated by a client who came to us last summer because he was having difficulty getting Medicaid. He was a young man with six children. He had been living and working in the Bronx. The children and the mother had Medicaid. Last spring, he moved his family to Suffolk County in hopes of a better life for his family. Sadly, around the time of the move, he became ill and could no longer work. He had liver cancer and needed treatment and medication. However, when he went to the Department of Social Services (DSS) they told him because the children and their mother had an open case in the Bronx, he could not get coverage until Suffolk County DSS had proof the Bronx case was closed. Incredulously, the Suffolk County worker stated their computer “did not talk to” the New York City computer system and they could not tell if the case had been closed. They suggested he go to the Bronx to get the case closed. This gentleman had no means of transportation. He had lived in the city his whole life. The family had no money. He and his children walked everywhere. You may recall that it was extremely hot last summer. He walked from his house to DSS several times a week, but was never able to get his Medicaid case open in time. We watched as he and his children would come into our office and he was sicker and sicker each time.

Since he had no insurance, when he had episodes of pain, he would go to the emergency department at the nearest hospital for pain medication and treatment. This he did on five occasions last summer. At no time did he ever receive any treatment for his cancer. The hospital discharged him, noting he had no insurance. In fact, when he was discharged, he walked home since he had no transportation or money. On the chart, the nurse notes sarcastically, “he says he has no phone”, as if she does not believe him. He died last week.

There is also the issue of denials from the private plans. We now get numerous calls from cancer patients asking for assistance. They are being denied authorization of medications because they categorize the drug as “experimental or investigational”. However, all providers use medications for off label use at some point to treat. Many standard and acceptable medical treatments rely on off label use of drugs for certain conditions.

For example, we had a young man with a brain tumor as our client. He came for legal assistance because his private insurance company denied authorization for the medication his doctor prescribed. The insurance company denied authorization because they determined the drug was “experimental or investigational”. In this case, the young man’s condition was grave. In fact, he had very little time left. He was a husband and a father of a small child. The drug was the only thing that kept him awake and alert enough to be with his family. There had been numerous published peer reviewed articles about effective this drug was with patients with brain cancer. Also, for safety reasons, it was the only medication this young man could take, but the insurance company denied it anyway.

Medications are not the only benefits denied by the private plans. We have several clients who became catastrophically ill while employed. Although their plans provided for long

term disability, they were denied. In one case, the client had provided volumes of doctors' records to the insurer about his condition. Because he had several co-morbidities, he had numerous referrals to specialists. He was denied because when the insurer sifted through the records, they found one notation from a vascular physician (not any of his treating physicians) who wrote "he could walk on his leg". The same insurance company then denied the life insurance to his widow when he died. He had worked at his company for ten years and the couple thought they were covered.

There are little or no reasons insurers should not deny authorizations and benefits. It is an economic decision for the companies. There are few, if any, legal ramifications to a denial of a necessary medication or treatment. They will not be sued if something happens to the patient because of the denial. The federal government through ERISA has provided safeguards to the insurers. Very few individuals, especially those suffering from cancer, have the energy or resources to fight the denials. The insurers know that it is too costly for the insured to hire an attorney to get their medication. Appealing the denials is difficult even for an experienced attorney. It can be insurmountable obstacle for someone who is very sick. Cancer patients should be fighting for their life, not with their insurance companies.