



Deborah's Story

Deborah is a native New Yorker who worked for 33 years. In 1997 she stopped working because she was becoming increasingly ill with bi-polar disorder. At that time she was in graduate school and working full time for New York City Housing Authority, Office of Alternative Education. When she left work, she was on welfare until her SSDI came through in 1998. Deborah is continuing her education and serves as a board member of two advocacy organizations.

"When I was notified that my prescription drug coverage was being changed to Medicare Part D, I was absolutely terrified. I started getting panic attacks again in the mornings. My blood pressure rose again – even on medication – I felt as if they had already taken away my medication. It's almost as if someone declared war on me and every other person with a disability who has to deal with this process. The complexity of having all of these companies to choose from was daunting, overwhelming. I wanted to make sure that what I enrolled in covered all my medications – these medications have kept me stable for all these years. I have general anxiety anyway so it led me to become even more anxious about my health."

When Deborah, a dual-eligible, explored the plan she was auto-enrolled in, they told her she would pay between \$1 to \$5 for her medications. "They said there was a three-tier system for medications – it depends on where your medications fit in the tiers." However, all dual eligibles pay \$1 to \$3 dollars. So Deborah says she spent a great deal of energy and anxiety trying to find a plan she could afford. She has found another plan, but this plan will not cover one of her drugs. Her new plan tells her that if her psychiatrist calls, they will put the medication on their formulary. Most plans require an appeal to include a non-formulary drug and it is unclear whether Deborah is getting accurate information from her plan. While Deborah waits for a resolution, anxiety is still an issue for her.

"I've contacted two plans about my medications and their coverage. In both cases, information I was given by the plans was inaccurate – in terms of medications covered, cost, and procedures to obtain an exception for coverage. I'm lucky, I'm pretty stable now so I feel that I can make an informed decision and I have the assistance of an advocacy organization, CIDNY. However, I'm still confused about the cost and procedures affecting my medication.

"What about people who haven't reached my level of stability and don't know about or have access to advocacy organizations that can help them pick plans. I saw a woman in the pharmacy who was screaming and yelling and crying because she wasn't aware that she was going to have to pay for her

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medications. There's a population of people who have been auto enrolled who are really in the dark and are paying far more for prescriptions and are being denied their medications and don't know that there may be other plans or options for them.

"What about people who have problems taking medications anyway and now they have a new barrier – now they stop taking their medications because they don't have the wherewithal to get through the system. That would have been me three or four years ago, when I had problems maintaining my complicated medication regiment."

"It took a lot out of me trying to understand what was going on with Medicare Part D. I'm making my way through this daunting system. What bothers me is that now I have to pay out of pocket, while I figure all this out. I am on a fixed income and I budget very carefully. The \$20 may not seem like a lot for others, but for me it means that there's some other basic need I can't fill because I'm now paying for my medications. Why is it that pharmaceutical companies that earn billions anyway now need this additional money? What is the necessity of Medicare D? Is it better than Medicaid paying for prescriptions?"

"People on fixed incomes have enough to worry about as it is. I was fortunate enough to have CIDNY to get the information I needed. I suspect there are a lot of people in my position with fixed incomes who are having a hard time choosing a plan and don't know about CIDNY or other advocacy organizations. How is this affecting their health and their budgets? Why should anyone have to choose between their budgets and their health?"