

A Common Struggle

I especially remember Steve Winter, a middle-aged man in a wheelchair who traveled to several of our hearings around the country, at his own expense. When he was growing up in Akron, Ohio, he did not realize that his mother had a mental illness. He did not understand that she had been diagnosed with schizophrenia and was taking medication – and didn't realize that when she started acting strangely, it was because she had stopped taking her medication. This happens a lot, often because when the medication works and the patient's symptoms lessen, they decide they are "cured" or "in remission" and secretly stop taking the meds. Or, in the case of Steve's mother, she had changed health insurance and there was some issue with her meds being covered under the new plan; so, since she was feeling okay, she just stopped asking for them.

One morning just after Christmas when Steve was fourteen years old, he was sitting at the breakfast table eating his cereal when he heard his mom yell. He kept eating but suddenly felt strange and, looking down, reached into his shirt and came away with a handful of blood. Then his mother stormed into the room holding a gun.

She yelled, "I shot your sister. I shot you and I'm going to shoot me so we can be in heaven together!" He was able to convince her to put the gun down and call for ambulances that came for all three of them. His sister was still alive, and while the bullet fired at him didn't hit any organs, it did hit his spinal cord and he was eventually left paralyzed from the waist down. His mother was hospitalized, not charged, and within a matter of months she was stabilized on medication.

Steve was not at these hearings for sympathy: "I'm not a professional victim," he always said. He wanted to point out just how much money his insurance company was paying for all his bills for his disability, millions and millions that wouldn't have been spent if the mental health system had been a little more proactive and had taken better care of his mom.

Steve's complaints mirrored those of many patients and family members who testified about being denied care – mostly expensive inpatient care, which was either refused altogether or withdrawn, without any real understanding of medical necessity, far before the patients were well enough to go home. Even when families had an inpatient hospitalization benefit of just thirty days, and with a high deductible, it was often hard to even get that: patients would be forced to go home after five or six days, or have their stays reviewed every two days, so instead of focusing on treatment, the families spent much of the time worrying their loved one would be prematurely discharged.