

Jeanette M. Castello

Personal Testimony at Public Hearing on SB 226

October 2, 2007

I am testifying today as a family member who has experienced the heartache and frustration of trying to help my daughter receive the treatment she desperately needed for her mental illness, an effort which was made more difficult by the current treatment laws that exist under Pennsylvania's Mental Health Procedures Act of 1976.

During a period of a year and a half, I watched helplessly as my daughter went through what seemed like endless crisis situations that required waiting until she reached the criteria of "clear and present danger to self or others" before she would be hospitalized and begin receiving treatment. After she was discharged, she would then stop taking medications because she lacked insight and didn't think she was ill, and then the cycle would repeat itself over and over again for a total of fifteen hospitalizations.

What that meant to me, as a parent, was that eventually I found myself hoping that my daughter would very quickly do something that would qualify as "clear and present danger" because I knew that she wouldn't receive any treatment until that happened. Simultaneously, I frantically worried that this time what happened might be too dangerous and that she would be seriously or irreversibly hurt. Because my daughter heard voices that told her to leave the house, she often wandered off at all times of the day and night, very delusional as she communicated in her mind with these auditory hallucinations. I wasn't able to stay awake 24 hours a day and therefore was not able to prevent her from endangering her life in her psychotic state of mind.

In case you're wondering if the reason she went through this constant cycling in and out of crisis and the hospital was because she lacked enough support or services, that was not the case. My daughter had contact with numerous psychiatrists, therapists, social workers, and intensive case managers and she attended day programs, an acute respite two-week program, and many group sessions during her numerous hospitalizations. The only thing lacking was an assisted outpatient treatment law, such as SB 226, that would have required her to continue taking prescribed medications. Another mental health professional, service or program would not have made a difference in breaking through her non-compliance with prescribed treatment.

Although I am also an advocate for an intensive, evidenced-based program called Assertive Community Treatment (ACT) which provides 24 hour crisis intervention and which I successfully advocated for in my county, even that program by itself would not have helped my daughter during this time of crisis because admission is voluntary and still would not have required that she continue the prescribed medications.

Dr. William Knoedler, co-author of the ACT Manual and the psychiatrist for over thirty years of an ACT program in Wisconsin, stated that 20-25% of the clients in his program were under court-ordered commitment and another 5% on probation/parole. He stated that, "for the most part [clients] respect the authority of the court order [to remain in treatment]." In addition, ACT is often used in conjunction with New York's Kendra's Law, the assisted outpatient treatment (AOT) law that SB 226 is modeled after.

You may be thinking, "Why did my daughter need to be involuntarily hospitalized so many times and why didn't she just understand the need to take prescribed medications?"

First of all, let me state that my daughter is an intelligent, thoughtful, caring young woman who I truly admire. In high school, she was a National Merit Scholarship finalist (one of ten out of over eight hundred from her high school). The answer to why my daughter didn't take prescribed medications is that as part of her brain disease, schizoaffective disorder, she also had a complete lack of insight that she had an illness, which is also known as anosognosia. According to the Treatment Advocacy Center, a national nonprofit organization dedicated to eliminating barriers to the timely and effective treatment of severe mental illnesses, "anosognosia is the single largest reason why individuals with schizophrenia and bipolar disorder do not take their medications." Dr. Xavier Amador, author of the book, "I Am Not Sick, I Don't Need Help!" states that "poorer insight is highly correlated with frontal lobe dysfunction [and this] has been replicated many times by various research groups." Dr. Amador has also stated that, "AOT is a vital tool that we need to help people who have anosognosia, or lack of insight, for mental illness."

I am not asking that you consider voting for SB 226 because my daughter and many other individuals have severe mental illnesses. Thankfully there are treatments that help and there is already research in the mental health field on these brain diseases. I'm not asking that you vote for this bill because we need additional mental health services, although certainly it makes sense to spend mental health dollars wisely on the best evidence-based services possible, such as ACT programs. I'm asking that you vote for SB 226 so that the small minority of individuals with severe mental illness and lack of insight to seek treatment on their own are treated compassionately and with timely treatment as we already do for our loved ones with Alzheimer's, another brain disease that often causes lack of insight and robs people of the ability to take proper care of their treatment needs on their own. Amending our Mental Health Procedures Act through SB 226 will change the dangerous Russian-roulette method of waiting for someone with a history of hospitalizations and/or incarcerations to receive the timely treatment they deserve.

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