

## **Some Thoughts from a Parent of a Child Suffering from Severe Persistent Mental Illness**

*(N.B. I am a parent of a consumer of mental health services, a consumer myself and a provider of those services.)*

My first mistake was charging at my son and grabbing him. He had called his mother vulgar, outrageous names. The end result was the three of us on the family room floor wrestling with a fireplace poker.

We made it through with only a bruise on my son. The emotional wounds were more significant. We added these to our earlier emotional scars.

We were already in family therapy. I called our therapist. She said, "Call CPS and tell them the story."

The CPS worker wasn't listening. He just put up with me until I said our family therapist had told me to call. I think then he realized there was already a written record of the incident in a file that could be subpoenaed. Then he asked me to tell the story from the start (so he could write it down and "cover his a\*\*"). We moved our son out of the house to live with a mentor for the next school year.

This was a turning point. We love our son. We always have and always will. We had already received some help but we needed more. What we received, unfortunately, was always too little too late. Both the mental health and the school systems let us and him down. The systems can be better.

Like so many others, our problems started at least a generations before my wife and I. My mother-in-law was diagnosed with schizophrenia and paranoia symptoms in her 20's. She was untreated until late in her eighties. The resulting emotional scars in that nuclear family were never discussed in family therapy throughout the 20+ years we accessed mental health services.

Looking back, there were troubling signs even before our son hit school. As a baby he was awake and screaming two or three times a night. I remember walking him in his bedroom one night when, exhausted and frustrated, I was fighting the thought to slam him into the bedroom wall. After eight months of this torture we finally closed the bedroom door and let him cry himself to sleep.

In his early grades in school our son would get up and wander randomly around the room. He was smart but he regularly lost his homework. He had lots of troubles with peers. Eventually, we had to move him to a larger school.

We were also willing to listen and make changes. We discovered along the way that some therapists were just plain incompetent and we fired them. We ended up with multiple diagnoses eventually shared by the family: ADHD, oppositional defiant, conduct disorder, anxiety, depression, addiction and co-dependency. Bipolar 2 later on as well. I had diagnoses, my wife had diagnoses, our son had diagnoses, our daughter had diagnoses. Looking back it's easy to see that because we didn't get adequate help, more diagnoses developed and they became more severe.

The option of divorce came up a few times. We put each of our kids out of the house for 6-9 months. The kids behavior was out of control and try as we might - I, my wife, and each of our kids - we could barely survive. We basically focused on getting them through school and keeping them alive.

If all we had were the resources of the mental health system, we would not have made it. Today my wife and I are happy in a marriage of 35 years. Our son and daughter are both married to loving partners. Our one biological granddaughter is thriving. I don't know why we made it and others didn't. I do know some of the things that helped.

My wife and I were part of a spiritual support group that accepted us unconditionally. We didn't expect understanding there, just acceptance. And we got it in spades.

We also had our own spiritual practices: daily meditation, meeting with a spiritual director each month, reviewing the day each night. I spent 60-90 minutes many times at 2am flat on my face on the family room floor begging God to keep a child alive. 12 Step spirituality and a community that helped me live with powerlessness was beyond important.

After several rollercoaster years, my wife and I accepted the limits of whatever we were going to receive in services from the mental health professionals. We suffered from our fears and the limits of our own personal resources. We decided to start finding a way to enjoy some time no matter what happened. That's when we started going to a movie once a week.

It cost us about \$1,000 a year and it was worth every penny. We both enjoyed movies. And we couldn't argue or catastrophize in the movie theater. That's a practice that carried us through 10+ years of family, emotional turbulence.

The recognition of a diagnosis of SPMI only came after my son became an adult, took responsibility for himself and somehow found purpose and meaning in years of suffering and misunderstanding. Our daughter found meaning and purpose in her daughter. My wife and I found ways to be gentle and forgiving and living in the present.

How could the system improve right now? I have to admit I'm working as a mental health therapist myself so I've seen the system from both sides. So this is just a viewpoint about two ideas:

1. Give up the “expert” role. Be expert but don’t use that to protect yourself. Even though mental health professionals may need to refer to consumers as “clients” in their notes, relate to them as consumers. That’s an attitude that professionals had who helped us whether it was called that or not.

2. Have the courage as professionals to agree to disagree openly with your therapy team. Learn how to do it. Do it regularly. Confront the reality that every client your team is working with is your client. Be on their side no matter what.