



## ***Surviving and Learning from a Child's Mental Illness: You Are Not Alone***

by Mrs. Smith\*

*\*All names have been changed to protect the privacy of the author's family*

If it takes a village to raise a child, then it takes a large city to raise a child with a disability. As parents we rely on the support of others, and our children require the support of various professionals to help them develop their potential and maximize their achievements. Yet, when our son was diagnosed with bipolar disorder in high school, my husband and I learned that once a child is diagnosed with a disability, the parents and child are often isolated with limited support.

Our son Jeffrey had always been a placid and easy-going child. In hindsight we see that the issues he faced as a youngster likely came from early-onset mental illness that increased in severity over the years. At the time we just attributed these issues to learning disabilities, and later to teenage rebellion. Difficulties in learning and executive functioning in elementary school became larger obstacles to Jeffrey in middle and high school, and they worsened when he began to use street drugs. I now know that there is a high correlation between abuse of substances and mental illness, but at the time I knew nothing of that. School staff and even the psychologist treating Jeffrey for substance problems were unaware of this fact.

Despite an Individualized Education Plan (IEP) for learning disabilities, Jeffrey was mostly left to flounder. The notion that one could be both highly intelligent and extremely challenged by learning disabilities had not yet reached educators in our area. Consequently, our son was placed in classes with low-performing students who did not participate and teachers who seemed unenthusiastic about teaching these students. Jeffrey began to model these behaviors, and our formerly happy son began to hate school.

After 8th grade we took him to an educational consultant who interviewed him and recommended several boarding schools. He attended a recommended school in 9th and 10th grades, coming home many weekends, for holidays and breaks. We later learned there was a great deal of drug use and violence in the dorms and that this was probably the worst placement we could have made.

In 11th grade Jeffrey returned home and attended a magnet public high school. He knew no one, had few friends, performed poorly in his classes and now had no IEP in place. (We allowed it to be terminated partly because we thought it could be stigmatizing when he applied to college. That was a mistake we came to regret.) Although Jeffrey still saw the psychologist he had been seeing since 8th grade to help him stop using drugs, his drug use was worsening. By 12th grade I was receiving emails two and three times each week from his guidance counselor saying he hadn't turned in his work, had missed classes, was in danger of failing. I asked his psychologist to see him twice weekly but she said she didn't have the time.

At home things also became worse. Jeffrey never mentioned friends, never had anyone come to the house, and seemed increasingly depressed. He had no energy and no enthusiasm. We took him to the pediatrician for his depression. The pediatrician recommended he see a psychiatrist but he had no way to help

us get in to see one without waiting a month or two. In the interim the pediatrician prescribed an anti-depressant. After about four weeks of this medication Jeffrey began to engage in risk-taking behaviors, including arranging to meet strangers with

whom he corresponded on the Internet. Meanwhile, he slept and ate very little. After yet another email from the guidance counselor saying Jeffrey was again missing classes and failing to turn in homework, my husband went to school to find Jeffrey wandering the halls in a daze, his shirt misbuttoned--looking like a homeless person.

We found a psychiatrist who immediately added a mood stabilizer and began to reduce the anti-depressant prior to stopping it completely. He did not tell us that Jeffrey had bipolar disorder. Within a day or two of this, my son got in a fight at school with the school bully, threatened to kill himself and left school. We reported him missing to the police but in a few hours he had wandered home. The next night he said he wanted to kill himself. We noticed cuts on his arms and we found he had cuts all over his stomach and chest

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too. He said the walls were breathing and he heard voices telling him to kill himself.

We took him to the hospital emergency room. Because the drug screen came back negative, the emergency room doctor said Jeffrey had schizophrenia. He was wrong. The hospital had no psychiatric treatment services for children under the age of 18, so we drove him to a psychiatric hospital. The intake nurse took his history and told us he had bipolar disorder. We found out that people with severe depression or severe bipolar disorder can experience psychosis and that is why Jeffrey was hearing and seeing things. He spent 8 days at the hospital, but the road to good health was much longer. With the right diagnosis we thought treatment services would fall into place and progress was near.

We contacted the schools and found the services they had for students with mental illness were not appropriate for Jeffrey, as they seemed to group together all the students with behavioral problems or mental illness. Jeffrey was fragile and paranoid; placing him with violent students would have been a mistake. The school said the social worker would provide us some referrals; however, she called only to say she knew of no services to help us.

The administrator of our county's Comprehensive Services Act said they couldn't provide any services unless Jeffrey was in foster care or under court supervision. The county's human services system for juveniles wouldn't provide services because we had private health insurance; we were not even permitted to meet with a county social worker. And the adult human services staff wouldn't meet with us because Jeffrey was not yet 18 (he was 17 and 9 months). The school drug prevention counselor knew only about prevention, not treatment services; and the organization that provides residential drug treatment services wouldn't treat those with mental illness.

Although we now had a diagnosis, we found a mental health system in shambles and a dearth of services,

a situation that I believe is not unique to my county or state but is nationwide. All of this placed a lot of stress on our marriage and our family. Some help came when we found NAMI and met other families like ours. It was extremely powerful to realize we were not alone. Though we are still angry that we failed to receive help from the schools and the public health system, we have channeled our anger into advocacy, working for more comprehensive services for young people with mental illness. Together with other parents we've established a support group to help counter the isolation and stigma we often face. In addition, we've worked with the schools and with county services to improve their understanding of and array of services for young people with mental illness.

But most importantly to us, our son now has a very full life. There were some close calls, some mistakes and the threat of criminal charges at one point. We owe much of Jeffrey's recovery to his own discipline, but also to the work of a wonderful psychiatrist Jeffrey has seen for almost five years for both therapy and medication. He included us in family therapy so we could learn about Jeffrey's illness and how to manage it. We also drew support from friends traveling similar paths with their own children.

Today Jeffrey is 21 years old and, by any measure, successful. He was recently hired into a six-month training program in a helping profession. He has a good salary, health insurance and a retirement plan. He is compliant with his medication, is happy and proud of his recent accomplishments. I would like people to understand two things: mental illnesses are biological disorders (like diabetes or high blood pressure), and people should not be blamed for having them (nor should parents be blamed if their child has a mental illness); and with some support and proper treatment people with mental illness can go on to lead productive and fulfilling lives. Our son has proved that. ■

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### **Lessons Learned Along the Way**

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- *Get recommendations for psychiatrists and psychologists from those in the profession or acquaintances who have gone through similar experiences, not from the list of recommended providers supplied by your insurance company.*

- *Do not feel wedded to a doctor you don't like. It is perfectly fine to get second and third opinions.*

- *You may be able to continue to cover your child with a disability under your health insurance. You will need a letter from your child's physician documenting the disability and that it impairs his ability to support himself at*

*this time. Don't wait until your child becomes ineligible for health insurance coverage to start this process.*

- *Reach out to other parents whose children have psychiatric disabilities. One way to do this is to join a support group. One in the Northern Virginia area for parents whose child, teen or young adult has a psychiatric diagnosis meets monthly. For more information you can contact NAMI for details and good publications at [www.nami.org](http://www.nami.org).*

- *Mental illnesses are biologically based brain disorders. Parents do not "cause" these illnesses.*

- *It is important to reach out and educate other parents, school staff, politicians and service providers. By speaking out we do make a difference and the mental health system will be much improved for your efforts.*

- *Stay hopeful about the future. Children and adults with mental illness can and do improve and learn to manage their illnesses. For a wonderful book about someone who has achieved huge success despite having bipolar illness, read Kaye Redfield Jamison's *An Unquiet Mind*. Is she exceptional? Absolutely, but so are all our kids!*