

Stigma

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William, the youngest of four children, the only son and much wanted, was born at a relatively easy time in his parents' lives. Graduate school was behind them, careers established, the mortgage no longer burdensome, and their three girls were doing well in school. They settled into a semi-rural community in the northeast, where they felt comfortable and had many ties of family and friends.

From age 2 William was a problem. At first it was hard to pinpoint. He was always darting back and forth and fidgeting. He did not seem to listen or even to hear. Unlike his sisters, he could not sit through a bedtime story. His sleep was irregular, gradually leading to all-night sojourns: his jumping, banging, and crying kept everyone awake. He took to throwing his toys out the window to watch them break.

At age 6, the problem extended to school. First, he was labeled impatient. Later, his interrupting, failure to follow directions, banging into other children, biting when he was angered, and lack of inhibition about taking others' possessions led to multiple consultations and periods of suspension. William did poorly in school, but not because he lacked ability. His numerous IQ tests put him in the normal range, but he simply could not sustain concentration, pay attention to detail, or follow instructions. He made mistakes or just did not complete assignments. He was described by professionals as "[having] poor emotional control," "can't attend to things," "doesn't appreciate others' concerns," "has had no peer relationships ever." Put simply, he had no friends and never had.

At 14, William was finally suspended from school because of his "odd" and inappropriate behavior. He was considered dangerous to his classmates. Since by law all children are entitled to education, he was assigned a Marine sergeant, who met him in the library each day for tutoring. William's problems were difficult to diagnose. He had accumulated an 11-year history of attention deficit/hyperactivity disorder before his illness reached a crescendo. But he had also received diagnoses of paranoid schizophrenia, autism, psychosis, Asperger's disorder, oppositional defiant disorder, conduct disorder, and obsessive-compulsive disorder, over the course of his parents' search for a treatment.

The family context relevant as background was uneventful. His sisters thrived, the oldest winning full scholarships to three Ivy League schools, the second following, and the third still in high school, popular, successful, and active in sports. William's clinical course remained also uneventfully bad, but stable enough through ages 9 to 14. He received "state of the art" treatment for his confusing and evolving condition: medication, counseling, tutoring, family therapy. The parents worked with several very caring physicians who kept young William on a functioning course. At age 14, his psychological symptoms took a more sinister turn and could no longer be maintained on his medication regimen. He became combative and physically dangerous at school and home. But, let his mother tell their story:

"During the year [1998] when he was experiencing extreme distress, I had trouble getting any treatment for him at all. The insurance refused to okay the full-scale diagnostic evaluation I wanted to have done at a university facility out of state that specialized in diagnostic perplexities of childhood. But they refused to admit him for evaluation even to the local regional psychiatric hospital. He was admitted to a psychiatric hospital finally, because I brought him there [an hour from home], on a day when he had seriously hit me and his sister, and we had visible marks. At the hospital, William also was verbally defiant and uncooperative with the screener. Yet it did lead finally to access to insurance-paid care.

"Once William was admitted to the psychiatric hospital, he did not stay very long. I was called on a Friday morning and told to take him home, because, given that he had not hit anyone or threatened anyone for 24 hours, he was no longer a threat to himself or others, and not covered by insurance. He received neither a diagnostic work-up nor treatment. On Saturday night, when he injured me again, I called the police, and they took him to the police station in handcuffs. A social worker interviewed me at the station and agreed that my son should be sent back to the hospital. On Monday, a judge met at the hospital with me, my son, a lawyer appointed for him, a social worker, and a hospital doctor and confirmed the readmission. I was billed for the social worker at the police station and the social worker at the hospital

setting. The insurance company refused to pay for the 'services' because I had not sought pre-authorization. I had just called the police. The insurance company did ultimately pay for the hospital readmission [only after the hearing with the judge].

"In seeking treatment for my son's psychological problems, I was frequently considered as the source of these problems: 'He is out of control because you need to be firmer with him' (when a retired Marine was unable to control him). 'He is non-compliant because you have insufficient structure in your home' (when his siblings are model citizens). 'He is a problem because you are too focused on him' (when clearly his problems were not going to go away by themselves). My attempts to provide background and documentation were seen as additional evidence of paying too much attention to his problems: 'You need to get a life' (when my son required constant supervision).

"In 1999 William's problems took an entirely new course. William became alarmingly pale and was brought to the emergency room of a regional hospital. When the doctor looked at his blood test, she saw possible evidence of abnormal white cells and told me that there was a chance he could have leukemia and that a larger hospital needed to do a bone marrow biopsy. Based on past experience I assumed that the case would have to be made to the insurance company for pre-approval and that there would be a long wait. Instead, she said that, in his condition, William would be taken immediately by ambulance to a larger hospital, and the test would be done immediately. This turned out to be the case. Within a few hours, acute lymphoblastic leukemia was diagnosed, and the next day, he had a central line [Hickman catheter] installed, and his chemotherapy began. The insurance paid for the doctors, the ambulance, the tests, the chemotherapy without an argument.

"My son's cancer was not considered as something that was 'cured' and no longer insurable whenever he was symptom-free for 24 hours. He had regular treatment and tests. When the tests showed relapse, he was immediately hospitalized and treated. "In participating in the treatment for my son's cancer, I was appreciated as a source of continuity and record in a teaching hospital where the on-floor residents and on-call hematologists change by the day or week or month. Since I spent virtually 24 hours at his hospital bedside, I was with him more continuously than anyone else. They knew they could count on me when they were treating one aspect of his condition, to remember the other. It was never suggested that I was overly concerned with his condition or his illness. It was recognized that a child's life-threatening illness is properly a parent's central concern.

"Among the professionals who dealt with my son's psychological illness, I frequently encountered irritation and threats aimed at him ('If you don't shape up' or 'I'm really having a problem with you today'), as if his psychological problems were subject to his direct control. In the 15 months of cancer treatment, I have never heard a nurse or doctor express any anger or irritation with my son for the symptoms of his illness. "The attitudes of the people not engaged in treating my son also reflected a difference between those who knew him as psychologically disturbed and those who knew him as a leukemia patient. For the mentally ill at the regional hospital, there are no volunteer visitors or "Smile Buddies" (college students who visit patients on a regular or temporary basis), as there are for cancer kids. Cancer patients are seen as brave fighters deserving of anything one could do for them: entertainment (glee club concerts, puppet shows), Halloween candy, prizes, and treats. The mentally ill are lucky if their families come to visit them. In fact, families are discouraged and visits limited, given that they are the 'prime suspects' for the cause of the problem.

"When my son was diagnosed with leukemia, I did not know much about the disease or its treatment. Most of my reading and research had been dedicated to his psychological problems. I did not know that the disease could manifest itself suddenly and I did not expect the bone marrow biopsy to yield a positive result. I assumed instead that the test would show that he had a mysterious condition, of unknown but suspicious origin, and that I would spend the next year trying to investigate and to seek diagnosis and cure, all the while dealing with multiple questions about myself. When I heard that William had leukemia, I was comforted in the midst of the bad news by the knowledge that, this time, there was a clear explanation for what was wrong, and a clear treatment plan, and that I could learn to be part of the solution instead of being considered as part of the problem. No one has accused me of causing his cancer."

William has just been discharged from the teaching hospital, which is 100 miles from home, two months after bone marrow transplantation. He was discharged from the first psychiatric hospital not when he was better, but when his insurance benefits ran out. To avoid infection, he is completing a 3-month post-hospital seclusion period in a hotel affiliated with the hospital. His mother stays with him. His condition is monitored closely. He was able to get a blood transfusion last week promptly when his hemoglobin fell. He will return home shortly and must remain out of school for medical reasons for 1 year. He will receive home tutoring. He had been discharged from the psychiatric hospital and psychiatric care not because he is mentally better, but because the buck has been passed. He still has the psychiatric problems, somewhat subdued by listlessness caused by the leukemia and its treatment. As his strength returns, so have his problems.

I told this mother's story to a dinner companion, who has an autistic son. He provided an epilogue. Autistic children look, act, and talk strangely. They have stereotyped body movements: clapping, rocking, and posturing. Family excursions were a nightmare. My friend's wife was reprimanded by strangers for not being able to control their son. The boy was stared at and ridiculed. These inventive parents, fed up with the situation, bought a wheelchair to take him about. The family was now asked about their child's disability. They were praised for their tolerance of his physical hardship and for their courage and the son for his bravery. Same parents, same child, different view. Stigma at all levels.

These are true stories. Obviously better understanding of William's underlying psychiatric condition leading to treatment is needed, but this is not unique to his condition. A full diagnostic evaluation at a facility specializing in his psychiatric problems may have been followed by more effective treatment. Even if no fully effective treatments were available or accessible, an evaluation could have had a salutary effect. By authoritatively labeling this boy as having a particular type of brain disease, the mental health workers might have been less likely to blame the mother for a child whose behavior was out of control. Fortunately state law required free and appropriate education up to the completion of high school. Since he could not attend regular school, the educational system authorized his admission to a residential school where the staff began to develop a program tailored to him. Unfortunately, this was just weeks before his leukemia was diagnosed. For his psychiatric condition, the legal system helped William get emergency care and the educational system provided his longer psychiatric care. The medical system took care of his leukemia.

If there were parity for psychiatric disorders, this inequity might not have occurred.

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Acknowledgment: The demographics, geography, names, and events have been altered to protect privacy. The mother, who is an acquaintance, gave full written consent and encouragement to tell this story and assisted in its preparation. Neither mother nor son were my patients.