



# BRAIN *Storms*

One family's struggle to fight stigma, wrestle with guilt and battle for access to the medical care their son desperately needed

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PHOTOGRAPHY BY TIMOTHY ARCHIBALD



Anne and Marcus Smith know they would use their real names for this article if their 14-year-old son, William, were suffering from a disease like diabetes or cancer. Their neighbors would likely deliver meals every time William was hospitalized and post affectionate messages on Facebook. But William has bipolar disorder, a chronic condition that causes extreme and sometimes disabling mood swings. And while Anne and Marcus could certainly use their community's support, they also have to guard their son's privacy to protect him from the harsh judgments people often make about kids with mental illness. So they share on a need-to-know basis, and the neighbors pretend not to notice when an ambulance pulls up to the house.

In many ways, William is like any American kid. He wears Vans and Levis, adores his dog and organizes capture-the-flag games with his siblings and friends. But, unlike most kids, William is among the 8% of American children who have an emotional disorder severe enough to significantly disrupt their ability to function in daily life—almost the same number as kids who suffer from asthma. William misses between one and two months of school every year, either because the thought of leaving his house is so scary that he feels paralyzed or he's been in the hospital to calm rages that sometimes end with dents in the wall.

Experts agree early treatment is crucial to preventing these diseases from continuing into adulthood, a critical fact when you consider that children with untreated psychological issues have higher rates of suicide and are more likely to drop out of high school, end up in jail or prison, or become homeless adults. Yet, the National Institute of Mental Health reports that only half of teenagers with a severe emotional disorder ever receive treatment from a mental health professional. In fact, it's common for parents to wait at least two years from the onset of symptoms to get treatment for a child with mental illness. While stigma prevents some parents from seeking help, a provider shortage—there are only 7,400 practicing child psychiatrists in the entire country, approximately one for every 600 children with a severe mental disorder—compounds the problem.

Anne and Marcus agreed to share William's story because they want people to know their son as more than just a boy with a very serious—and very misunderstood—disease. He's the fun-loving kid who always raises his hand to be the magician's assistant. The outgoing teen who persuaded his entire family to join the conga line at Disney World. Most of all, he's a child who deserves your compassion, as well as your concern that more isn't being done to help the 4.3 million children like him who suffer, largely in silence.

## “We didn't know how to get in the loop.”

Finding the right care for a child with mental illness is like navigating an obstacle course...while blindfolded.

Typically, parents first turn to their child's pediatrician, only to be referred for a diagnosis to a specialist, who will likely have a months-long waiting list or not be accepting new patients. From there they may need to find a psychiatrist to discuss medications (which could also take months) and then potentially get a referral for a new specialist who is trained to treat their child's specific condition. Throughout, they'll be filling out stacks of insurance paperwork and spending hours on hold trying to confirm all treatments are covered—while shuttling kids to Little League, getting dinner on the table and juggling every other aspect of daily life.

That was roughly the experience for Anne and Marcus, whose son has been struggling with what seem like tornadoes churning through his brain since he was a toddler. When he was 4, he told them he felt so terrible that he wanted to throw himself down the stairs and go live with the ghosts in the cemetery. While he was usually able to hold the brain storms at bay in elementary school, William often fell apart as soon as he walked through the door of his family's Minnesota home, exploding into rages for an hour. He head-butted Anne and bit and kicked Marcus to the point where Marcus spent a summer in long sleeves to cover up the welts. When the rages subsided, William was always overwhelmed with sadness and remorse, requesting hugs from his mom and dad. Why, he asked his parents, did life have to be so hard?

While Anne and Marcus were in the minority of parents who sought help while their child was very young and have managed to afford that help, finding the kind of specialized care that he needed felt like an almost insurmountable challenge. “We didn't know how to get in the loop,” says Anne, “because we didn't even know where the loop was.”

Their experience incenses advocates like Congressman Tim Murphy of Pennsylvania, the only practicing psychologist in the House of Representatives or in any elected federal government position, for that matter. After the 2012 shootings at Sandy Hook Elementary School in Newtown, CT, he launched an extensive review of the country's mental health system. What he found was a chaotic patchwork of antiquated and uncoordinated programs. “Everywhere I went in the country,

## CLASS ACTION

### HELP YOUR KID'S SCHOOL MAKE AN IMPACT.

It may be hard to believe, but the majority of teens who do receive help for mental illness get it at school. Unfortunately, there's a nationwide shortage of psychologists, counselors and social workers in educational settings, which means far too many kids are falling through the cracks. That's why experts are advocating for additional mental health training for teachers so they can help identify children in crisis. “If a student has his head down on his desk, a teacher may think he's lazy or bored,” says Jennifer Greif Green, PhD, an assistant professor at Boston University's School of Education. “But I want teachers to also consider that this student might be depressed.” Washington, DC, is taking notice too: Senator Al Franken of Minnesota is currently pushing to amend the current No Child Left Behind law to enable schools to partner with community organizations to provide mental health services for students. If you want to advocate for increased services:

→ **Reach out.** Ask your school social workers, psychologists and counselors what they're already doing to support student mental health and how you can help them get more support in the district.

→ **Request numbers.** Invite your child's principal or school psychologist to sit down and discuss mental health services. Then ask them to collect data on the mental health needs of students, the availability of treatments and teachers' knowledge of both. This data can be used by the administration to identify students who need more support, develop teacher training topics and define areas of need for additional resources.

→ **Join in.** “If a child is denied a bone marrow transplant, we parade the problem in front of the public,” says R. Scott Benson, MD, a child and adolescent psychiatrist in Pensacola, FL. “Because of the stigma associated with mental illness, parents are reluctant to go public with their plight.” But you can get involved in community-wide events designed to raise awareness about mental health and the resources that should be devoted to it. The National Alliance on Mental Illness ([nami.org](http://nami.org)) has campaigns you can join. Or support Congressman Tim Murphy's bill by writing to your local representative. You'll find contacts at [house.gov](http://house.gov) and [senate.gov](http://senate.gov).

people told me, 'I tried to get my child help and we were turned away,'" he says. Murphy has reintroduced a bill, the Helping Families In Mental Health Crisis Act (H.R. 2646), to address these challenges with initiatives that range from forgiving student loans for physicians who go into child psychiatry to increased federal research funding for treatments that are scientifically evidence-based.

Anne and Marcus desperately hope those changes come sooner rather than later. When they talk about William's disease, they sometimes pull out a bulging six-inch stack of folders with tabs indicating anything from hospital discharge records to painstakingly detailed medication charts to scholarly research on behavioral therapies. The documents are a paper trail of trial and error, including 30 different medications and 13 diagnoses—William's current ones are bipolar affective disorder without psychotic features, obsessive-compulsive disorder and generalized anxiety disorder. It's a sobering reminder that no matter how hard parents try to find the best help for their child, scientific research for mental illness lags far behind the resources that are poured into childhood physical illnesses.

It might be surprising to learn that while there have been revolutionary advances in the understanding of the teenage brain, adolescent psychiatry is still more art than science. "There are thousands of ways to combine symptoms to determine a diagnosis," says Jay Giedd, MD, chair of child and adolescent psychiatry at UC San Diego School of Medicine. "So you try to come up with an insurance-friendly way to phrase things." Because 50% of chronic mental illnesses begin by age 14, doctors know it's crucial to figure out how to get treatments covered as early as possible.

Anne and Marcus first consulted a child psychologist when William was in preschool, hoping to learn strategies for parenting an out-of-control child. As William's rages intensified, his care expanded to a team of specialists, who eventually suggested they consider hospitalization to stabilize him. While Anne and Marcus knew William's weekly therapy appointments and monthly medication checkups weren't enough—he was taking Prozac and Risperdal, an



antipsychotic drug used to treat bipolar disorder—the thought of hospitalizing a boy who was still sleeping with stuffed animals felt like a line they were not willing to cross. Until one spring day when the stakes became too high to keep thinking he was safe at home.

### **“I didn’t want to leave my baby.”**

If you’ve ever had a child go missing in a crowd, you’ll understand the terror Anne felt the day that, at the end of a fourth-grade field trip, William bolted across the street from a public playground into some nearby woods. He’d been playing on a slide when a classmate teased him. Anne was sitting with the other chaperones, nervously watching the scene unfold because she couldn’t tell whether William would simply cry or go into a rage that could scare the other kids. (William has never been violent toward anyone but his parents.) When he took off, she raced through brush-clogged paths to find him, knowing for certain that William needed more assistance than he could receive at home. She called Marcus and told him that once she managed to get William into her car, they were driving straight to the hospital.

Any frustrations Anne and Marcus already felt with the mental health care system were magnified tenfold the minute they walked through the doors of the hospital’s emergency room. Because its pediatric ER didn’t have safety protections for potentially violent patients, protocol mandated that children requiring psychiatric care be admitted through the adult ER. Security officers stood outside William’s examination room. The Smiths waited six hours for a bed in the hospital to open up. “The system is so overwhelmed,” says Congressman Murphy, who also regrets that the Smiths didn’t have access to intensive outpatient options. “People often aren’t able to get help until their lives are falling apart.”

The situation was even bleaker in the child and adolescent behavioral health unit. Because the doctors had no way of knowing whether or not William was violent enough to hurt himself or others, he was placed in a unit behind a locked door that they entered through a hall of lockers, where visitors stored their belts, shoelaces and ties. Inside, the walls and furniture were all dirty shades of taupe; TVs were covered in smeared Plexiglas. A stack of broken chairs with a “Warning” sign stood near the entrance.

William was so terrified that he didn't say a word unless a doctor or nurse asked him a direct question. Leaving him alone for the night was out of the question, so Anne and Marcus persuaded the hospital staff to allow Marcus to sleep there. Anne remembers this as one of the worst moments of her life. "I sat in my car and cried and cried," she says. "I didn't want to leave my baby in a locked room. But I didn't know what else we could do."

Experts who work with kids like William see firsthand the toll a disease like this takes on the entire family. "It's so hard for parents to keep their wits together and sit calmly as they watch their child go through such a terrible crisis," says R. Scott Benson, MD, a child and adolescent psychiatrist in Pensacola, FL. "It helps to stay calm when someone is falling apart, which is difficult. But I know that we'll be able to pull them back together, even though it takes time."

The hospital stay was traumatic for everyone, although Anne and Marcus praise the doctors, nurses and staff, who they say were extremely caring and attentive. The doctors prescribed a med wash, discontinuing all pharmaceuticals so they could start from scratch to determine which medications were most effective. The process was arduous and felt more "let's try this" than rigorously scientific, but it eventually stabilized William to the point that, after nine days, he could go home. Hospitalization also gave William access to a team of specialists at the top of their field as well as outpatient day-treatment options that had previously been unavailable to him. Anne and Marcus had learned enough from their experiences to insist that his hospital psychiatrist become his outpatient physician as well.

William has been hospitalized four times since then, with each stay lasting between five days and three weeks. (During those periods, his parents are permitted to visit and can even stay the night.) He hates being away from his family, but the experience no longer feels like prison now that a new unit, which looks more like a modern Scandinavian dorm than a hospital, has opened. His parents have come to accept it as well. "The only way to get the kind of intensive

psychiatric care that William sometimes needs is in the hospital," says Anne.

## "Each good day creates healthy connections."

William is just starting ninth grade, and while he still cycles through rages, he's maturing and is often able to avoid situations that trigger his storms. Now that he's in puberty, his brain is at a stage where it could either mature well or develop a more serious illness. "In a sense, each good day in the child's developing brain creates healthy connections and each bad day creates unhealthy connections that are harder to change over time," says Giedd.

Because William has received high-quality care since he was very young, Anne and Marcus have more reason to feel hopeful than the families of kids who haven't had access to a team of qualified specialists. But they're also keenly aware that they are in a race against time. Current Health Insurance Portability and Accountability Act (HIPAA) laws state that when patients become adults (anywhere from age 14 to 18, depending on state law), they can choose who is on their health care team. Anne worries that if she and Marcus don't have a solid relationship with William, they won't be able to help him get to his appointments or give new doctors his medical history. Congressman Murphy's bill proposes to change the HIPAA laws to allow parents to be their child's advocate past age 18. "A case worker with 50 to 70 people in their caseload isn't the same as a loving family with a caseload of one," he says.

If you met William today you'd notice that while his face is becoming more angular, he's still enough of a kid to blush at Will Ferrell movies. Anne and Marcus hope for research and legislative changes that will lead to not only a greater scientific understanding of his illness but also more compassion and support for families like theirs. If William eventually wants to go public with his diagnosis as a way to fight stigma, they will proudly support him. In the meantime, they take comfort in William's everyday triumphs, including the joy he feels when he plays Magic: The Gathering with friends and goes fishing with his dad. They hope that more and more of his life will tilt in favor of the funny and sweet boy they adore. "He can be such a bright light," says Marcus. "It's astounding."

### familycircle.com

For info on finding a doctor, resources for kids with mental illness and more, go to [familycircle.com/mentalillness](http://familycircle.com/mentalillness).