The Public in Public Policy

Stories from North Carolinians with Mental Health Challenges

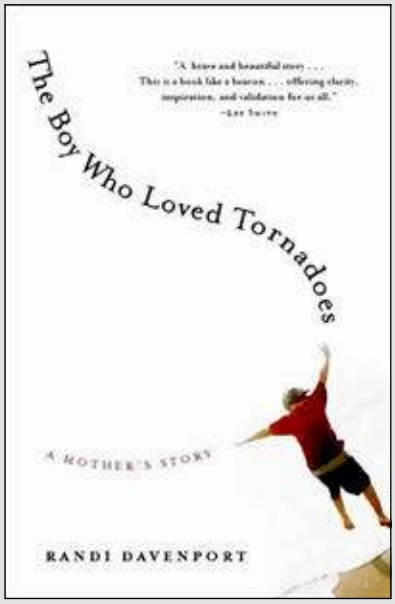
Editor's Note: One of the goals of the Center's Strategic Plan for 2012–16 is to "increase the use of stories of people affected by our research." It is important to see the faces and hear the stories of the public in public policy and to understand that real lives are impacted, for better or for worse, by changes in policy.

No Place To Go

by Randi Davenport

I noticed her as soon as I arrived at the podium. She sat in the back with her purse on her lap and a tense expression on her face. As I read from my book about my son's mental illness, she leaned forward. When I finished, her hand shot up. She was counting on me to save her family. But I knew that neither I, nor the latest in health care reform, would provide the help she needed for a loved one facing chronic mental illness.

They come to my readings in droves, these women with lost children, siblings sleeping on the streets, parents vanished into worlds beyond reach. One woman stood up and said, "Tell me what to do." She had a wrenching tale of not being able to find services for her son. Others send email messages. "I knew the minute I read your book," one wrote, "that you were the person with whom I must speak." Another said, "I will do anything." They describe their loved ones: "My daughter who is 23," "My son who is 14," "My sister abandoned by our parents." They share stories of unspeakable loss and pain. I hear them clearly. They need answers. They need to save someone. And they believe that I can help.



I can't. I know no better than they do how to wring services from a state that has made cuts or from an insurer that refuses to pay. But I have deep sympathy. I used to be just like them, calling everyone I could think of, saying, "Please. Please." I could be just like them again, at any moment, with one stroke of the pen.

My son, now 22, suffers from a disorder that includes features of both autism and a psychiatric illness. Just exactly what is wrong with him has eluded experts from Duke to UNC to Yale. When he was hospitalized with a baffling psychosis, I found myself on a self-guided tour of our mental health system just as some of the worst budget cuts were getting underway. I heard of states that stopped funding group homes, sending the sick into the streets; of parents forced to quit work and go on welfare to care for a child no provider would take; of residents of private group homes living on powdered milk because it cost too much to buy milk in a carton. I did *not* hear of providers willing to take patients whose clinical picture disrupted the business model. The most disabled were left with no place to go.

Randi Davenport is the author of The Boy Who Loved Tornadoes*, a book about her son's mental illness.*

"I'm Back, Baby!"

by Laura Anne Middlesteadt

I was 41 when I experienced my first mental illness — a wicked battle with Generalized Anxiety Disorder. I had led a pretty charmed life until my thirties, but then a series of hardships — my mother's accidental death, infertility, layoffs, and finally a disastrous cross-country move — tipped me over into relentless anxiety. My family and I ended up turning around and moving back across the country to the East Coast because of my mental state, which I attributed to our new location. Of course, by then I needed medical treatment, but I didn't understand that at the time. I waited until I had gotten a job and my insurance had kicked in before seeing a doctor. Once I did, a standard dose of a common antidepressant turned me around in a month — but the damage was done, both to our family's finances and to my marriage.

Although I remained healthy, my husband ended up moving out a year-and-a-half later. I stayed on my medicine and got through what initially seemed like the end of the world. I did so well, in fact, that a little over a year later, I decided I didn't need an anti-depressant anymore and stopped taking it. Four months afterwards, my divorce was finalized, I had to put my dog to sleep, and my doctor ordered an MRI to look for brain tumors — all in the same week! In hindsight, it appears obvious what would happen, but I didn't see it coming at the time. In a matter of days, anxiety had me in its unbearable grip once again.

Treatment was not so straightforward this time. Although I restarted my medication, I felt worse initially and made the irrational decision to stop taking it. My doctor then ordered a different medication, which was disastrous for my digestive system. I began to lose weight rapidly. At this point, I was referred to a psychiatrist for the first time. I had to drive out of town to find one who was accepting new patients. A period of constant flux followed — additions, subtractions, and dose changes in my meds, while I got sicker and sicker and saw my hope for recovery dwindle to nothing.

I had two suicide attempts in two weeks: an overdose and a violent attempt to kill myself. I ended up in a large hospital in a nearby city for more than seven weeks. I spent three weeks in intensive care and three weeks in the psychiatric ward. When I was released by a judge in January of 2008, I stood 5' 7" and weighed 93 pounds. I had had two major surgeries and was covered with scars. My short-term memory was impaired. I was unable to work, drive, care for my son, or live on my own.

I had a million obstacles to overcome at this point, but I had one key advantage: I was no longer anxious. My old standby medicine, at the old standby dose, had kicked in sometime while I was in the midst of my feverish morphine dreams.

I have to credit my recovery to medication, because without it, I never could have been well enough to benefit from recovery's other key components: a great counselor, a wonderful family, the responsibilities of my job, my son, running my household, and my own determination to get my life back and "make it up" to everyone. I wrote encouragement to myself in my journal: lists of goals, things to do to make myself feel better, helpful mantras, and a list of everyone who supported me. As I began to gain the weight back, I took many well-documented baby steps back toward my normal life. Privately, I celebrated each one: buying jeans that fit, getting my teeth cleaned, and baking a cake.

In June of that year, four months after my release, I bought my first house since my divorce. After that, my recovery really took off. The day of the closing, I finally wrote the words I'd been waiting to write in my journal: "I'm BACK, baby!"

Too Fearful To Sleep

by Gloria Harrison

Like lots of Geminis, I embody the duality of nature. I love to laugh and play and am also full of despair and sadness. I like to read and frustrate myself with politics. I have a dog, Lefty, who is the light of my life. His politics consist of a belief in benevolent dictatorships, as long as he is the dictator. In order to get away from him for at least eight hours a day, I work at the NAMI (National Alliance on Mental Illness) North Carolina state office and answer the Helpline. I have taken calls from around the state for 20 years.

My diagnosis is depression with episodes of psychosis. I have also had insomnia for my entire life. I had several bouts of severe depression as a child, including two suicide attempts before the age of 16.

One of my worst days came at the age of 36 when lack of sleep and despair had me locked in the bathroom at 4:00 a.m. I was holding a butcher knife in case demons or burglars or whatever tried to get me. I thought there was no difference in that episode from hiding in the bathroom of the orphanage all night as a child, too fearful to sleep. That thought prompted me to completely give up on life.

I was always told that I was difficult to love because I was so isolated and took myself too seriously. However, after starting on medication, I actually came out of my depression enough to realize that it wasn't all my terrible "nature." It was a treatable illness.

I have been on antidepressants for 25 years, and so far, my liver is still talking to me. I attended group support meetings for 15 years and still participate in other kinds of support, including using the Internet. I have been happily married for 10 years. Of course, we have been married for 37 years.

Acceptance, Family, and Friends = Recovery

by Deb Johnson

My diagnosis of bipolar disorder II came after six long months of physical pain, an exhaustive mania, and a sudden crushing depression. I was lucky enough to have a friend who was around me frequently enough to suggest that I see a psychiatrist. She had bipolar disorder and recognized the symptoms. My diagnosis was not a surprise, and—though it may sound trite—it was a relief to have an illness instead of just "crazy Debbie behavior."

Though I accepted my illness easily, I can't say my recovery was smooth sailing. Medications introduced into my system took weeks to begin to take effect, and my depression deepened as I waited. The first six months of treatment were complicated by a diagnosis of diabetes, a miscarriage, and a burst gall bladder—all testing my ability to stay the course of therapy, psychiatry, and medications.

My husband was my saving grace. His unwavering love and understanding had him curled up in dark corners with me as I contemplated suicide. He waited with me silently until I was ready to move again. My friends asked questions and educated themselves to help understand what I was going through, and they provided tough love when they noticed changes before I did.

Yet for all the love and assistance I have readily available, I have not been able to escape relapse completely. Learning to understand my triggers and creating an action plan to avoid them has been immensely helpful. I've found mini-episodes to be situational and typically beyond my control. Thus, I have an action plan in place that includes outside support.

And then there is relapse. I had no action plan for complete relapse as it has only happened once in the 12 years since this wild dance began. In March of 2009, a work-related issue sent me into the dark places that no one likes to talk about. It lasted for almost a year. Like any episode, a relapse brings about new information, new avenues of help, and new perspectives. Medication, doctors, and the love of family and friends helped me rise out of the darkness once again. I am stronger now—comfortably dancing between the broken places in my world of acceptance and recovery.