
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 2012–2016 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.

In April 2014, Senator Fletcher Hartsell (R-Cabarrus) implored the mental health community at a legislative breakfast, “Tell us your story. Become real to us.”

The Cost of System Failure: Losing Josh

by Julie Jarrell Bailey

“Mental health system failure is personal and it's painful. It has different names for different people. In my case, system failure is also known as Joshua, Jacob, and Isaac Bailey.”

The state estimates that there are 230,776 children in need of mental health services across North Carolina. Another 45,321 need substance abuse treatment. A fraction of those get the care they need—50 percent of the kids needing mental health treatment and 9 percent of those needing substance abuse treatment are served.

For me and for many people in North Carolina, the failure of the mental health system isn't just about numbers, budget cuts, a lack of services, or political will. Mental health system failure is personal and it's painful. It has different names for different people.

Meet the Bailey Family

In my case, system failure is also known as Joshua, Jacob, and Isaac Bailey. When my husband, Steve, and I adopted these three brothers from the state foster care system in 1996, Josh was eight, Jacob was

seven, and Isaac was four. We decided to adopt from foster care because being a parent meant more to us than parenting an infant. We believed then as we do now that every kid deserves a loving, caring home, regardless of their age.

The Department of Social Services (DSS) classified all three of our boys as “special needs” because each had a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD). This meant they were eligible until age 18 for Medicaid, the state-run federal program providing health insurance for the poor, long-term care for the elderly, and services for persons with disabilities. But ADHD was just the tip of the iceberg for our boys, and it took us about five years to build a more complete story about their histories and problems. Among other things, we learned that we were Josh's ninth home, Jacob's tenth, and Isaac's fifth, including back and forth attempts at reunification and living with biological family members.



The DSS profile photo of the boys in 1995 as provided by the foster system.

Accessing Treatment and Education for the Boys

By the time Josh arrived in our home, he was what we described as “fighting mad.” He managed to keep his anger hidden from Steve and me for about two or three days before lashing out at Jacob over a whiffle ball game in the front yard. He chased his brother with the plastic baseball bat, hitting him and calling him names, saying he hated him and hated all of us. He ran away, and it took more than two hours of following and talking to him with non-punitive words to entice him back home.

We placed the boys in a private school. Josh and Jacob were in a combined classroom that covered grades one and two. We had frequent calls about the two of them being disruptive in the classroom and calling each other names. It didn’t seem as though they liked each other very much, but we were determined to help them learn to be a family again.

It took us from April until June of 1996 to find a therapist and medication manager who would accept the boys’ Medicaid insurance as payment. After our psychiatrist moved to private practice and then passed away, we had to begin the search for a new Medicaid provider all over again. In the interim, we secured a therapist and psychiatrist who accepted our private Blue Cross Blue Shield insurance with co-payments each week, which quickly became very expensive for three children in treatment. By 1999, we had moved all treatment services to the Orange-Person-Chatham Area Mental Health Program.

All three boys struggled with school. When we moved from Chatham County to Orange County to

be closer to treatment, we enrolled Josh and Jacob in public school while I home-schooled Isaac for kindergarten. In fourth grade, Josh was tested at UNC-CH and we found he had a severe learning disability. We requested that the school implement an Individualized Education Program (IEP) plan for him based on the testing scores from both the school and UNC. While his math scores were acceptable, his reading scores were that of a first grade student. During one meeting, the school principal asked, “Mrs. Bailey, why is it that you think your son can’t read?” I said, “I don’t think Josh can read because when all of his little friends were learning their ABCs, Josh was learning how to dial 911. That’s why I don’t think Josh can read, sir.” By the time we left the meeting, Josh had an IEP.

Out-of-Home Treatment for the Boys

Each boy has needed more help than we could provide at home. Despite therapy and medications, the boys had severe behaviors that included expressing extreme rage, self-harming behaviors, physical aggression at everyone in the family, running away, destruction of property, school issues and more. The diagnoses for each of them expanded from ADHD to include Bipolar Disorder, Post Traumatic Stress Disorder, Reactive Attachment Disorder, Oppositional Defiant Disorder, Generalized Anxiety Disorder, learning disabilities, and additionally Rage Disorder for Josh and Isaac while Jacob’s diagnosis included borderline features.

Our Child and Family Team felt the Wright School in Durham would provide the best treatment for the older boys because of the school’s behavior modification and remediation model. The Wright School is a state-operated residential treatment facility for children with severe emotional and behavioral disorders. Josh was 12 years old, the cutoff age limit for Wright School student, and there was a waiting list. After about three months of waiting, Josh was accepted into the program a few months before his 13th birthday. A month after Josh entered the Wright School, Jacob’s application was accepted. Out of 24 beds in the entire facility, we felt very grateful to have two of them.

Josh thrived at the Wright School. He won awards, his grades improved, he finally felt confident in himself, and he returned home seven months later as a new person. He became more thoughtful, compliant, and engaging. He still had struggles and challenges, but the changes were significant and the

parent education provided us tools to help sustain him at home.

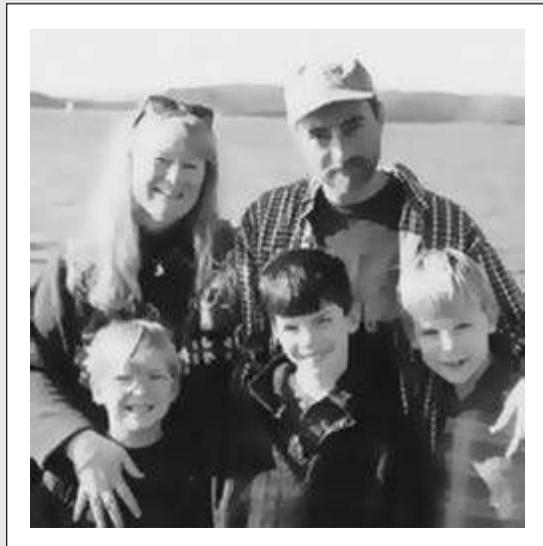
Jacob did not return home from the Wright School. After about seven weeks in the Wright School program, he tried to commit suicide by hanging himself on the playground after finding a short piece of rope. His brief stay there was just the beginning of numerous residential placements and hospitalizations over the years, including Eliada Home in Asheville, Youth Focus in Greensboro, Gateway in Durham, and multiple placements at the adolescent treatment program located at Butner.

In his later teen years, we were fortunate Jacob was accepted into the Whitaker School, which I compare to a high school version of the Wright School. His treatment and supports there were helpful. He was discharged the day before his 18th birthday and quickly had some setbacks. He eventually ended up living in a Family Care Home. It wasn't an appropriate match, but there were no beds anywhere in the state designated for a transitioning young adult with mental illness.

Once an adolescent with mental illness turns age 18, the resources and options are greatly reduced. Unfortunately, Jacob's poor coping skills, anxiety, and impulsiveness caused him to be moved to four different Family Care Homes in less than a year because they were not equipped to manage his mental illness and emotional/behavioral outbursts. None of the Family Care Homes provided any therapeutic supports. That wasn't within their service definition.

His move into a group home for adults with mental illness in Durham made move number five, but it didn't last long. One day, he just left. Supervision was poor, and it was easy for him to walk off. His treatment provider at the time said they weren't going to respond to his phone calls for help because he needed to live on the streets for a night or two to teach him a lesson. We argued that Jacob would not learn the lesson they described, but instead he would learn he could actually survive on the streets, and it would make it more difficult to get him to agree to return to a group home. They refused to provide him assistance when he called, even though he told his case manager that he was scared and asked for someone to come pick him up. He promised to return peacefully to the group home, but they left him on the streets of Durham. They wanted him to learn their lesson.

Jacob's one or two nights on the streets turned into seven months of homelessness and growing dysfunction compromised by drug and alcohol use. That was in 2008. Since that time, Jacob



Bailey family at Smith Mountain Lake in 1998.

has experienced additional hospitalizations and group home placements. In 2011, his last lengthy hospitalization, Jacob's treatment team changed his medication to include the drug Clozaril. This medication has provided Jacob with a high level of stabilization. As a result, he's lived in the same group home for nearly three years. He has just completed a vocational training program, which has given him skills in carpentry, and he's hopeful of becoming gainfully employed. He is invested in his own recovery plan and is happy with his life's direction. So are we.

Isaac never attended the Wright School, although in hindsight, he should have. Instead, we worked at providing his treatment at home, utilizing Multi-Systemic Therapy and Outpatient Therapy. Finally, in 2007–08, as puberty and adolescence conflicted with his mental health issues, Isaac went to Eliada Home in Asheville for out-of-home treatment. His coping and self-management skills improved there, but we had to engage Intensive In-Home Therapy when he deteriorated in the fall of 2008.

The Realities of the Transition to Adulthood

For many young adults, turning 18 is a relatively easy, exciting transition. They plan for college, trade school, military service, or jobs in the community. They fantasize about what being a legal adult means. For some, it means they no longer have to ask their parents if they can go out for a night on the town. Some move out and live on their own for the first time.

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For young adults with a mental health issue, and especially for their parents, turning 18 is scary. These kids are not equipped to cope with the stress and pressure of being adults. This has been the case with all of my children, and I hear the same reports and concerns from other parents in similar situations. Our kids tend to take common developmentally expected behaviors in young adults to the ultra-extreme. What was considered to be at-risk behavior when they were children becomes high-risk behavior as young adults, often dangerous and with serious consequences.

Many parents tell me that their transitioning adult children choose to stop taking their psychiatric medications and disengage from therapy. My kids did this in their bid for independence. Once a child turns 18, parents are no longer consulted by treatment providers in therapeutic decisions. Despite having a mental illness, the law states that an 18-year-old is a legal adult and can make their own choices. The law applies to the abled as well as the disabled, unless a parent secures legal guardianship. Steve and I learned this the hard way.

Josh's Story

Josh was always too busy quieting the demons in his head to allow support services to be very effective. His anger escalated, and at home he was physically aggressive against all of us, even pushing Jacob down the stairs and attacking Steve and me while we were driving the car. He was about 10 years old when we hospitalized him the first time. Yet, he managed to hold things together better in public settings. He worked desperately to keep a smile on his face and fit in. Being accepted by everyone he knew always seemed to be more important to Josh than learning how to conjugate verbs.

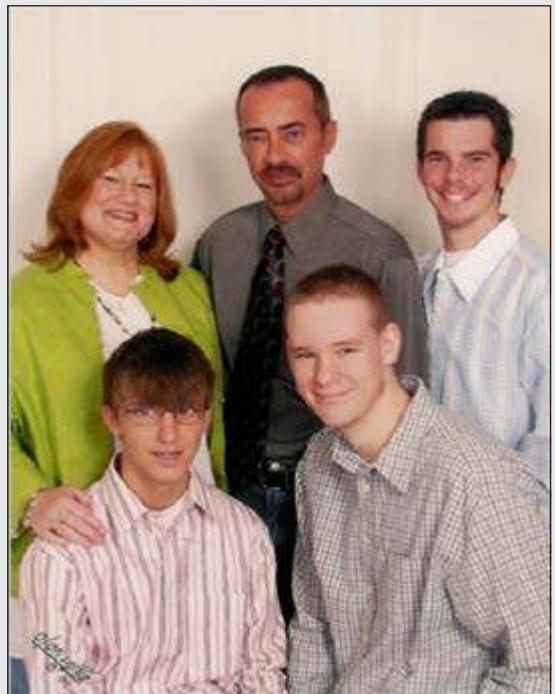
For Josh, talk therapy was never very productive. He was a secretive child and didn't like talking about his past. When the boys joined our family,

they each came with a Life Book created by their social worker. Josh's Life Book contained a photograph of him with Jacob that I always loved. They were very young, maybe four and five years old. The photo shows them playing in the kitchen cabinets, and they are laughing really hard. It's a precious photo.

One day after therapy, I was alone with Josh when he asked, "You know that photo you always like of me and Jacob as babies playing in the kitchen and laughing real hard?" I said, "Yes, I love that photo." Josh said, "Well, I need you to know that we weren't laughing in that picture. We were crying. That was the day the social workers came to take us away. We were hiding in the kitchen cabinets, but they found us and took that picture before taking us away from our home."

By the time Josh got to high school, his academics were in sad shape. In 11th grade, we moved him from public school to a charter school with a curriculum that better supported students moving into a trade rather than those who were university bound. Steve and I had come to accept that Josh was not university material, and that was okay with us. We just wanted each of our kids to be happy and to find a way to support themselves after high school. His

The Bailey family in 2006. The three boys faced the transition to adulthood within four years of each other. Josh, upper right, was the oldest child.



school conducted aptitude testing, and it supported career paths that already interested Josh, including culinary arts, the retail industry, and fire/rescue work. They helped Josh get a part-time job at a local grocery store working as a bagger and cashier. It was great experience for Josh, and he continued bagging groceries past his 2006 high school graduation. But his growing experimentation in alcohol and drug use triggered cycles of mania and depression that worsened with each episode.

He had turned age 18 in 2006, and his legal adult status meant that Steve and I were no longer allowed inside his therapist's quarters. We weren't consulted about his medications either, despite having a lengthy history to provide of what had and had not worked over the years. We were totally discounted as members of Josh's treatment team. Also on his 18th birthday, Josh lost the Medicaid insurance that he had had since foster care. He was on our private Blue Cross Blue Shield plan as long as he stayed in community college, which continued to provide his medications and therapy on a co-pay basis until he dropped out of school at age 19.

Steve applied for assistance with paying for Josh's medications with one of the drug companies, which was helpful. He asked the treatment provider to accept Josh on a sliding scale fee, which they did. We even drove him to his appointments to make sure he showed up because by this time, he had moved deeper into the drug culture and often missed appointments. He was spending many nights away from home to party with friends, which kept Steve and me awake all night worrying. He was in a hypomanic state for a lengthy period of time, and we were helpless to prevent him from spiraling.

He finally ran away from home. He lied to the parents of his friend, telling them we had kicked him out so the parents would take pity on him and let him stay. He called every few days to let us know he was okay and told us the name of his friend but wouldn't say where his friend lived or give us the name of the kid's parents. After about three weeks, Josh cycled into depression and was ready to come home. We got him back into therapy, on medication, and into Alcoholics Anonymous (AA), which he attended seven days a week. He started to resume some normalcy in his life and went back to work to learn skills as a butcher.

About two months later, he hit another manic cycle and ran off for a few days to party. When he cycled through the mania again, he was ready to go back to work and refocus. He couldn't understand

why his employer wasn't as forgiving. We made a plan for him to enter Caramore Community. In the beginning, he was successful. He didn't mind the work and got along with his house mates. He attended AA meetings again. Then, like clockwork, two months later he had another manic episode and didn't return to the facility for a few days. When he contacted us after these episodes, he was always remorseful, and there were always consequences. This time Caramore said that Josh no longer met the criteria to remain in their program, and they discharged him in early April 2008.

The difference in this situation and previous episodes was that Josh refused to come home. He was 20 years old now. He had experienced brief periods of independence and liked setting his own schedule while disliking our house rules. What 20-year-old doesn't? He told us he was going to stay with a friend in Burlington. When the friend moved back to town, Josh came with him. They were in frequent party mode. We did see and speak with him frequently. He got a temporary job with UNC food services that didn't last long. He did some construction work. He mowed lawns. Mostly, however, he came by to see us at our jobs, which was easy because Steve and I worked in the same building. He wasn't able to maintain consistent employment and needed money for food and cigarettes.

One day in late June 2008, Josh met with us to ask for help in getting into a rehab treatment facility. He said he realized that his life was going nowhere, and he had reached rock bottom. He wanted to turn his life around with our help. We were ecstatic. He came home for a family gathering over the Fourth of July to see his grandparents, aunts, and cousins from Florida and local family too. He talked to Steve and me about wanting a new start. We invited Josh to come back home, and he said he might do that after his grandparents returned to Florida. My mother had stayed with us for three months for cancer treatment at UNC, and Josh was concerned about crowding us. Over the course of the next few weeks, we saw Josh every day as we worked towards helping him reach his goals.

When he visited us on July 21, 2008, his physical appearance was concerning. He looked very dirty, and some of his clothing was torn as though someone had tried to yank off his shirt. We asked him about it, and he said, "Nah, I've just been mowing lawns for money, so I'm dirty." We made plans for a family cookout each of the next two weekends, and he was going to call us to pick him up on Saturday. That call never came. When he missed the second

weekend, which was my birthday, we knew something was wrong.

On August 5th, Steve and Isaac went to the Chapel Hill Police Department to file a missing person's report. The officer told Steve that Josh was a legal adult, and if he didn't want to call his parents, he didn't have to. Steve explained that Josh had Bipolar Disorder and was not on his medications. We were used to seeing him every day, and it had been two weeks, so we were very concerned. The officer said it didn't make a difference that Josh had mental illness. But he did say he would take the flyer we made and announce it during shift announcements.

August 13th was the date we had set to fly my mother back to Florida because we had a wedding to attend on August 16th. A close friend here called while we were in Florida and said she spoke to a friend at the Orange County Sheriff's Department who told her we should come visit him when we got home from our trip. He was willing to help us launch a missing person's report. We caught an early flight home and Steve spoke with Investigator Tim Horne on August 19th.

One of the first things we learned was the officer who spoke to Steve at the Chapel Hill Police Department was misinformed. The department could have taken Steve's missing person report on Josh. Tim opened an investigation to determine why Josh was missing and where he might have gone. He enlisted the assistance of Special Detective Phillip Stevens with the State Bureau of Investigation. A Silver Alert was issued to the media. We were contacted by the National Center for Missing and Exploited Children and paired with a couple whose daughter had been missing for 10 years. I broke down in tears wondering how we might emotionally survive if we had no answer for 10 or more years.

Our experiences and lives became surreal. On Friday, September 12, 2008, we saw a news clip about a friend of Josh's named Matt Johnson, and it reported that he had been kidnapped. Steve had given investigators Matt's name. The news report gave us hope that Josh had been with Matt, and they had been kidnapped together.

By morning, we were feeling defeated and stupid for thinking Matt might know anything. Steve and

Josh on fishing trip to the Keys for 20th birthday in 2008.



Isaac decided to take a drive up to Smith Mountain Lake, Virginia. He used the excuse of “work” but he really wanted to go see if there were any signs that Josh had been staying on our boat.

About 30 minutes after Steve left, Tim Horne called, asking for Steve and said he had several more questions. I told him that Steve had taken off for the lake, but I could reach him by phone. Tim said I should call Steve, which I did. Steve said he would turn around and head home. I was supposed to leave for a pottery class, so I called to let them know I would be late. Then I went out to sweep my porch. As soon as I started sweeping, I saw Tim walking up the sidewalk, and we started greeting one another. Then out of the corner of my eye, I saw someone else. I looked up and saw my pastor, Ray Warren. The last thing I remember is the sound of my voice screaming, “No, no, no, no, no...”

While my memories are sketchy, I am told that we were given the names of six young men who were involved in murdering Josh, including Matt Johnson. It took nearly five years after Josh’s murder for the first person to come to trial. Our District Attorney, Jim Woodall, felt that it was important to first try Brian Minton since he was the alleged ringleader in Josh’s kidnapping, torture, and murder. A jury agreed with him and sentenced Brian to life in prison plus 30 years. Four other defendants have accepted plea bargains and will serve anywhere from 25 to 38 years in prison for their role in Josh’s murder. The fifth defendant was sentenced in Spring 2014 to life in prison without parole for the kidnapping and murder.

Both of Brian’s parents pled guilty to obstruction of justice this past December 2013. Mishele Minton had driven her son to Lowe’s Home Improvement to purchase muriatic acid to pour on Josh’s body so it would not be found. Superior Court Judge George Abernathy said, “I just can’t conceive of what kind of person would want to assist someone in just desecrating a body with acid. I can’t conceive of somebody that is so evil they would assist in buying acid so that a mother and dad would never find out what happened to their child.”

Steve and I are emotionally drained and physically exhausted from the legal process. Our roller coaster ride through the legal system only taught us that there is no such thing as swift justice nor is there anything resembling closure.

The life of Joshua McCabe Bailey meant a great deal to us. Steve and I fought and advocated for him every step of his life. The frustrating thoughts are

““ Our roller coaster ride through the legal system only taught us that there is no such thing as swift justice nor is there anything resembling closure. ””

that it shouldn’t have to be so complicated for kids, young adults, or anyone living with a mental health issue. I wish Josh could have felt more comfortable with who he was and could have embraced his mental health issues. It definitely would have helped him further with his recovery process.

The system failed Josh before he was born by failing his birth mother. My descent into hell is defined by “what ifs” ...

- What if their birth mother had received the help she needed as a child?
- What if the Department of Social Services had conducted mental health assessments of the boys?
- What if when Steve and I adopted the boys, we had been introduced to our area mental health agency and educated about the mental health system of care?
- What if the justice system had kept Brian Minton behind bars for previous arrests and charges instead of releasing him?

The reality is that none of these “what ifs” will bring our son back to us. We prefer to help other parents raising kids with mental health conditions in the here-and-now so they don’t have to experience a nightmare similar to ours.

Julie Jarrell Bailey has worked for 10 of the past 14 years as both a staff member and volunteer with the Family Advocacy Network (FAN), a program at Mental Health America of the Triangle (MHAT). Julie served as Interim Executive Director for MHAT for 15 months in 2010–2012. Prior to her work in the field of mental health, she worked as a journalist and public relations professional. Julie is the author of the book “The Adoption Reunion Survival Guide: Preparing Yourself for the Search, Reunion and Beyond.” Along with her husband, Steve, Julie is co-founder of Josh’s Hope Foundation, Inc., a nonprofit organization in Hillsborough, NC, working to bridge gaps in services for transitioning young adults with mental illness.