

Interviewee: Randi Davenport

Title: Raising a mentally ill child

Duration: 7 minutes, 56 seconds

About this transcript

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Introduction

Our healthcare system poses challenges for people with common diseases. The system for children with mental illness is exponentially more frustrating.

In this episode of Bookpod, Randi Davenport talks about *The Boy Who Loved Tornadoes*, the book she wrote about the near-impossibility of finding effective care for her mentally ill son.

Presentation

The Boy Who Loved Tornadoes is a memoir about our family's struggle with both autism and mental illness. My son, Chase, who is now twenty-two, was diagnosed very early on with a series of developmental issues. They could never really pin down exactly what it was that was going wrong for him and with him. So by the time he was a year old, he had a global developmental delay diagnosis, and he had a severe ADHD diagnosis. He had a pervasive developmental disorder diagnosis. He had Tourette Syndrome diagnosis.



When he began to exhibit mild psychotic symptoms when he was about five, psychologists and psychiatrists were not really certain whether or not those were really psychotic symptoms. They thought, well, perhaps we can explain these by putting them in an autism category.

So by the time he was six, he had an atypical autism diagnosis. And then eventually he developed a seizure disorder. And just before his fifteenth birthday, he ended up entering into a true unremitting psychosis.

We'd been living in the rural Midwest where I was teaching at a small college. There were no services for a child with autism, certainly not fifteen years ago. The state where we lived had a policy for families struggling with a wide range of developmental or mental health disabilities. They would give you a check, I think it was for \$200, every month, and you could get yourself any therapy you wanted with that \$200. And of course \$200 might buy you an hour's worth of therapy with a child psychiatrist.

While we lived in that state, my family encountered suggestions like, "Buy a padlock and lock your child in a



room." Or, "Put a fence up around the backyard so he stops running away. Use the money to do that."

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So I learned about the TEACCH autism program in North Carolina and thought, "I'm going to come here, and I'm going to take care of Chase and Haley, my daughter, by taking care of Chase."

I abandoned my career as a professor and came to North Carolina to get Chase appropriate care – therapeutic intervention – which helped in the beginning but which did not go far enough.

So coming to North Carolina was a sign of great hope and optimism and certainly an effort to try to get Chase on track and get him moving forward. And certainly that's the language that I used in the moment – that all I needed to do was find a way to get him on track, and the family situation would improve.

There were more services here than there were in the rural Midwest. We were able to participate in the Community



Alternative Placement program, the CAP program, which enables care providers to come into your home and make certain that your loved one stays in the community.

Unfortunately, the CAP workers that we had come into our house ranged from people who were really competent and really good and had significant training and experience to late adolescent boys who were, you know, in college and really had absolutely no idea how to handle anybody or help anybody. And so it was in the care of one of those workers who failed to give my son his anti-seizure medication on the schedule that was put in place by his doctor that caused my son to fall and break his neck during a seizure.

So there are ways in which that program creates a kind of false sense of hope and security in families, the sense that you are, in fact, getting some kind of services when what you're really getting is a person, another body in your home.

The battle became the battle to find Chase services. And very few places would even look at him. In the state of North Carolina, you have to have either a developmental



disability diagnosis or a mental health diagnosis. You can't have both. If you do, then you're not going to find any services. And that was my experience.

The more I struggled and the more doors closed – and I called everybody you can imagine – the more helpless and isolated I became. And the more determined I became to find a solution. And so I would try to bring people together to think creatively about solutions, kind of use the resources that were available to create a new solution for Chase.

And of course, people were locked in place in the system and couldn't do much of anything. Somebody said to me, "You know, getting a lawsuit going would be the way to get services."

At that point I was thinking of my son, who was so medicated that he spent most of his time in the second psychiatric hospital he was in, the one he, in fact, arrived in after my insurance company refused to pay for him anymore, so he went into the state psychiatric system. He spent most of his days kind of nodding off and drooling in the day room.



And I looked at the records after he was released, and really they just had an aide that looked at him every fifteen minutes and made certain he was still breathing. He was just warehoused in this large state psychiatric facility.

So there I was, watching him fade away. And I thought a lawsuit would be the thing that would kill him, that we would have hostility between attorneys. We would have many, many years of maneuvering, motions and counter-motions, and in the midst of it I would lose Chase.

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You know, at the suggestion of some colleagues here at the university, I went to visit with a man named Bill Friday, who is in fact an incredibly generous and gracious man and who had the ability to intervene on our behalf. And so he did.

So he was our miracle. He saved Chase's life. He's a man who used his power for kind of a just and humane intervention, which is extraordinary. I'm very grateful to him.



At the same time, I'm acutely aware of the fact that this is not how families should have to get services; that it was the luck of the draw, really, that allowed me to know this man who could help us. But most families do not have that kind of access. And because they don't, that only underscores how immoral and unethical it is that we have a system in place that does not serve families unless the very powerful intervene.

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I don't know if there are ways in which I can explain to listeners that each of us has deep, deep, deep cores of strength that we don't realize that we have.

And so when you think about the love that you have for your children, you think about what you would do for them. You would do anything for them, I think. And that would include changing your life path if you need to.

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I do remember going out and standing in the front yard from time to time at night and looking up at the stars and breathing in the wind, and hoping for something better and, in fact, asking for something better. But I don't know that



that really counts as self-care. You know, mostly I just had to be ready every single day to stand up and put one foot in front of the other and go forward. And I think that's what most parents would do.

Valedictory

Randi Davenport says that Chase is “flourishing” at the Murdoch Center in North Carolina. Her daughter Haley is headed for college in the fall of 2010.

Bookpod producer is Barbara Finkelstein. Music is by Kevin MacLeod. This episode was recorded by Will Bosley at the Beasley Media Resource Center of the University of North Carolina at Chapel Hill.

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