



The public radio show about law and American life

Justice Talking Radio Transcript

The Rights of the Mentally Ill—Air Date: 8/20/07

State laws permit the involuntary commitment of people suffering mental illness if they are a danger to themselves or others. But how do these commitment laws work in practice? Do laws aimed at protecting patients' rights prevent those people from getting the help they need? Are they violating their civil liberties? The law and the mentally ill, this week on Justice Talking.

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MARGOT ADLER: From NPR, this is Justice Talking. I'm Margot Adler. The shooting at Virginia Tech last spring has reopened the debate over court-ordered treatment for the mentally ill. The state can step in if someone is thought to be an immediate danger to themselves or others, but should government intervene sooner? A journalist talks about the struggle to get help for his son.

UNIDENTIFIED MALE: Unless you go in and tell the folks in there that he threatened to kill you, we'll take him to jail instead of a hospital.

MARGOT ADLER: And an established law professor reminds us that not everyone with mental illness is dangerous. She comes out about being schizophrenic.

UNIDENTIFIED FEMALE: People with schizophrenia read the newspapers and we see how we're portrayed and it's, you know, you tell at great risk.

MARGOT ADLER: Coming up after the news.

MARGOT ADLER: This is Justice Talking, from the University of Pennsylvania's Annenberg Public Policy Center. I'm Margot Adler. On today's show:

UNIDENTIFIED MALE: The face of mental illness right now in this country because of Virginia Tech is Mr. Cho. But Mike Wallace is the face of mental illness. He has depression. He's spoken about it. Patty Duke is the face of mental illness. Patrick Kennedy is the face of mental illness.

MARGOT ADLER: According to the National Institute of Mental Health there are 56 million American adults living with some sort of diagnosable mental illness. Most people find ways to manage illnesses like depression and bipolar disorder, but sometimes mental illness can lead to destructive behavior. And in the wake of a tragedy like the shooting at Virginia Tech in April, lawmakers and citizens are left to wonder how someone so clearly in need of help slipped through the cracks.

On today's show: What are the laws around treating someone with a mental illness if it's against his or her will? We'll also talk to a mom from Ohio who had to give up custody of her son when she could no longer afford to get the mental healthcare he needed. More than 12,000 families in the United States have had to make a similar choice. It's devastating to be a parent, watching one's child suffer with a mental illness like bipolar disorder. Pete Earley knows this all too well. He's a former reporter for the Washington Post and the author of "Crazy: A Father's Search Through Mental Health Madness." The book looks at why there are so many untreated mentally ill people in the country. It begins with Pete's own personal story. He's rushing his son, Mike, to the hospital near his home in Virginia.

PETE EARLEY: Well, my college-age son Mike had been diagnosed with bipolar disorder while he was in school. He'd been given medication. He was doing fine. Then he stopped taking his meds. And for five days he was wandering around New York aimlessly, believing that God was giving him secret messages. His brother called me from New York and said, Dad, you gotta get up here. Mike's gone crazy. So I hopped in the car and I raced to New York. And I, Margot-- that ride was just incredibly painful. My son Mike would laugh one minute and then he would begin sobbing the next as if he were being tortured. And he said to me: Dad, how would you feel if someone you loved killed himself? And I raced him in the emergency room and the nurse rolled her eyes as Mike told her about messages that God was sending him. And then we were taken to a waiting room which is what we did for four hours. Finally Mike said I've had enough. I'm going to leave. I said, hang on, hang on. And I raced out and I flagged down a doctor. And I'll never forget how he entered that room. He came in with his hands up as if he were surrendering. He said: Mr. Earley, I can't help you with your son. I said: You haven't even examined him. And he said it doesn't matter. The nurse had said that Mike believed all pills were poison and in Virginia it is against the law to forcibly medicate or treat anyone unless they're in imminent danger to themselves or someone else. So there's nothing I can do. And then he said to me, bring him back when he tries to kill you or he tries to kill someone else.

MARGOT ADLER: So as you sat in that hospital waiting room, um, would you have really wanted him committed to the hospital against his will?

PETE EARLEY: I wanted him helped. We knew that he had a diagnosis of bipolar disorder. We knew that medication helped. We knew that he was not thinking clearly. You know, I took

my son home, and I watched him get sicker and sicker and sicker. At one point he slipped out of my house. He broke into another person's house--luckily, they weren't there--to take a bubble bath. Five police officers wrestled him down. He was fighting for his life. They took him to a community treatment center. I went there. The policeman, who was waiting outside, said: Mr. Earley, even though your son has a mental health diagnosis, even though you know medication helps, even though he's been hospitalized twice before, he still doesn't meet imminent danger criteria. Unless you go in and tell the folks in there that he threatened to kill you, we'll take him to jail instead of a hospital. So I went inside, Margot, and I lied. I said my son had threatened to kill me. And that was good enough to get him into a hospital for 48 hours. Then I thought, well, at least our problems are over because he voluntarily committed himself. Because he still didn't meet that imminent danger criteria, I don't believe, if we'd gone before a special justice. And just when I thought things couldn't get worse we got a call. The Fairfax County Police were charging him with breaking and entering and destruction of property, two felonies that would be marked on his career.

MARGOT ADLER: What was the ultimate outcome of your son's arrest?

PETE EARLEY: The people whose house my son broke into wanted him put away. They wanted him locked up for life. We were very fortunate in that the detective took sympathy on my son. She realized he was sick and needed help not punishment. She persuaded them to let us have more time to come up with a treatment plan. He ended up pleading guilty to two misdemeanors rather than felonies and voluntarily went on two years probation.

Let me tell you two quick things. One: That detective was Vicki Armel from Fairfax County. Two years later she was murdered by an untreated 18-year-old man in Fairfax who had a mental illness, drove to a police station, and simply opened fire, killing her and another officer. Secondly: My son did great on the two years he was on probation. He got a job. He got promotions. He was employee of the month.

Two months after that probation ended my son stopped taking his medication. He became psychotic. Fairfax County has a mobile crisis response team. I called them and I was told: How sick is he? I explained that he was off his medication. He was becoming delusional. They said: Is he violent? I said no. Call us back when he's violent. When my son did become violent I called the same Fairfax County mobile response team, talked to the very same dispatcher, and he said: Oh, he's violent? We don't come if he's violent. Call the police. My son ended up getting Tasered twice and hog-tied.

If I couldn't get my son help after spending two years investigating our mental health system with my knowledge of the system, with my political connections through the Washington Post, with my money, with my education, then what chance does someone who doesn't have money, who doesn't have political connections, and has no experience, maybe they don't speak English, what chance do they have in Fairfax, Virginia to get help?

MARGOT ADLER: How's your son doing today?

PETE EARLEY: He's doing much, much better. He is back on his medication. He has got a part-time job. And he gets furious if anyone refers to him as bipolar disorder or he's bipolar; he's more than his illness. And I'm proud of him and I'm hopeful that this time we will avoid getting arrested and getting Tasered.

MARGOT ADLER: You ended up using your personal experience with your son's mental illness to investigate a larger question: what happens to the mentally ill? You spent time while writing this book at a prison in Miami, researching the mentally ill who end up in jail. You've written books on criminal justice before. You've spent time inside some of the country's worst prisons. What surprised you most when you went back and began looking at the prison system, specifically with the mentally ill in mind?

PETE EARLEY: Well I was shocked at how many persons with bipolar disorder and schizophrenia and severe and persistent depression are in our jails and prisons: 16 percent. Right now as we're talking there are 365,000 people with bipolar disorder, schizophrenia, and persistent depression in our jails and prisons, 500,000 on probation, 700,000 go through the criminal justice system each year. The largest public mental facility in the United States is not a hospital. It's the Los Angeles County Jail. So I began this investigation and I looked to the past to learn why we're in this situation. Why are people with mental illness in jails and prisons? One was deinstitutionalization, which was not done out of kindness. It was not done out of concern. It was done about money. States were facing problems with these ancient, barbaric warehouses where people were sent and just forgotten. They had to fix them up or they had to close them down. Civil rights groups were filing suits trying to improve the services in these hospitals. So the states were backed in the corner and the federal government came in, said we'll make people eligible for Medicaid and other benefits but only if they're not in the state hospitals. And overnight the states voted to dump these people in the streets without having any kind of safety net.

MARGOT ADLER: People who work in the prison system or have studied it often refer to the revolving door that applies to mentally ill inmates. Talk about that.

PETE EARLEY: Well we're not talking about Hannibal Lector serial killers. We're talking about people who have brain disorders. Many of them have been homeless living on the streets for 15 to 20 years. They get picked up for something like urinating in public. They're taken to the jail because they're charged with a misdemeanor. They can't be forced into treatment. They can't be forced to take medication. Within 24 hours they're turned loose back to the streets, completely untreated. One of the persons in my book, Freddie Gilbert, had been homeless for more than 12 years. He had been arrested more than three dozen times, and so he was in this revolving door. He was costing the city of Miami more than \$70,000 a year just in services, like this getting arrested, going through the court system, and never getting any help.

MARGOT ADLER: What finally happened to him?

PETE EARLEY: He's still there. He's still in that revolving door.

MARGOT ADLER: Do you think the mentally ill inmates that you profiled in your book were dangerous? How did this group compare, for example, to inmates you've spoken to or investigated for other books?

PETE EARLEY: Persons with mental illness are unpredictable, and by that they can be dangerous. Now everyone cites studies that show that persons with mental illness are no more dangerous than the general population. And it's very, very important to remember that this group I was studying is a small group who end up in the jails and prisons. What's bad is persons with untreated mental illness who are allowed to continue to get sicker and sicker, like my son, and we won't step in until they become violent. We need some common sense. Look, my son doesn't believe that terrorists attacked during 9/11. He thinks George Bush is behind it, okay? I don't have a problem with that. But when my son has a history of mental illness, when he's off his medication, when we know medication helps him, when he is psychotic and thinks the CIA is listening to his thoughts, and he's sitting in front of a television, and we know that he tends to become violent, why do we wait for him to cross that threshold?

MARGOT ADLER: Pete Earley wrote the book "Crazy: A Father's Search Through Mental Health Madness." Thank you so much for talking with me.

PETE EARLEY: My pleasure. Thank you.

MARGOT ADLER: Coming up on Justice Talking: He was once committed against his will but now this lawyer advocates for involuntary treatment.

UNIDENTIFIED MALE: There was nothing I wanted least, or less, than treatment. I was thrown in a hospital. I stayed there. I got well. I got the medications that took away my symptoms. What did I do? I went back to college and I went to law school and now I work to help people who are like I once was.

MARGOT ADLER: And a civil rights attorney says not so fast.

UNIDENTIFIED MALE: We would never tell a cancer patient that she was required to take the treatment that a doctor said. We would never tell someone with diabetes that we know better than you. In this particular instance we've got to move to a place where mental and physical illnesses are seen in the same kind of way and where the rights to choose or to refuse treatment are honored in both.

MARGOT ADLER: Stay with us.

MARGOT ADLER: This is Justice Talking, the public radio show about law and American life. I'm Margot Adler. On today's show we're talking about treatment laws and the mentally ill. These laws are referred to in a variety of ways: forced treatment, assisted outpatient treatment,

and involuntary outpatient commitment. The question boils down to this: When can the state step in and tell someone they have to get treatment for their mental illness? I'm joined by Michael Allen and Jonathan Stanley.

Michael Allen is a lawyer specializing in housing and civil rights issues with the firm of Relman and Dane. He previously worked with the Bazelon Center for Mental Health Law, where he led efforts to oppose involuntary outpatient commitment. Jonathan Stanley is the acting executive director of the Treatment Advocacy Center. It's a nonprofit organization that supports involuntary outpatient commitment for the severely mentally ill. Welcome both of you to Justice Talking.

JONATHAN STANLEY: Thank you.

MICHAEL ALLEN: Thank you. Good to be with you.

MARGOT ADLER: Jonathan, your organization has been a longtime supporter of forced treatment laws. Why?

JONATHAN STANLEY: Well, basically starting in the late '60s and through the '70s the treatment laws were changed drastically. From being rather broad and open as to who could qualify, they were narrowed to only people who were in immediate or imminent danger to themselves or others. We saw the results of that by not being able to get treatment to people with illnesses like schizophrenia. We saw our jails and prisons and streets fill with people suffering from the symptoms of these disorders. So we think that we don't have to go back to where we were before, but at the same time a reform may be to the point where people who are incapable of making rational decisions can qualify for commitment is the rational way to go about it.

MARGOT ADLER: Forty-two states have some version of these laws and in some states like Virginia a person must be proven to be in imminent danger to themselves or others before they can be forced into treatment. In other states like New York, the threshold is lower. A person only needs to be showing signs of deterioration that they could become a danger to themselves or others. Jonathan, isn't that a sort of slippery slope, the idea that a judge could make someone get treatment against their will based on a hypothesis of what they might do in the future, a kind of preventive detention?

JONATHAN STANLEY: Well we're not talking about people who are fully medicated and their symptoms are under control. These people have uncontrolled symptoms of mental illness, in most cases, that make them incapable of making decisions concerning their welfare. This is the same kind of standard that we use for people with Alzheimer's. We don't let infants decide their treatment either. When someone is in such crisis that they can't take care of themselves, we feel that it is society's obligation to step in and help them until once again they can manage their own care.

MARGOT ADLER: Michael, I'd like you to weigh in here. Don't a lot of people with mental illness slip through the system, not getting the help they need, not even realizing that they're ill?

MICHAEL ALLEN: Well, I'd take issue with this point that Jonathan and his colleagues have made for a number of years about the lack of insight into one's mental illness. I think more often the barriers that we see, Margot, have to do with the unavailability of community-based services, that people don't get services not for a lack of wanting them but simply because of waiting lists and rationing that mean that they do in fact slip through the cracks. The real reform that's necessary here is a reform to look at holistic mental health services, comprehensive services, and to make those available up front rather than, as Jonathan would do, wait for people who fall into crisis and then bring the full force and coercion of the state and a court order against them.

MARGOT ADLER: Jonathan, I've read a figure that about 50 percent of people with mental illness don't know they're sick, but you'd agree that that doesn't necessarily mean they're dangerous.

JONATHAN STANLEY: No, absolutely not. But going to Michael's comment, when we say 50 percent of people with mental illness, we're not talking about people with mild depression or OCD or something like that. We're talking about the most acute illnesses, psychotic disorders principally. Disorders that can make someone hallucinate, think they can fly, have delusions, think they're on another planet or their parents are robots. We're talking about the most severe symptoms and we're not talking about people that are going to access services, no matter how good they are on their own initiative, because they don't think that they're sick.

MARGOT ADLER: Michael, how do you respond to that?

MICHAEL ALLEN: I think the critical thing here is to realize that even people in deep crisis, even people who have been failed by all the other elements of the system are being helped by practical and creative programs such as Pathways to Housing in New York City, which has housed over a 1,000 people who have active mental illness, probably co-occurring substance abuse disorder, and a number of other complicating factors. To do that, Pathways has been able to couple or link all sorts of services and supports people need to get back to wellness and to recovery and that their results have been remarkable. We don't need coercion, Margot, what we need is constant outreach and assertive community treatment.

MARGOT ADLER: So, Jonathan, what about that issue that this would be solved much more if we had just better community services for the mentally ill?

JONATHAN STANLEY: First of all, I'm not gonna argue against better community services, because they're vital. But it's a distinct question. There is what is available to treat people and for the small sub-set of people, the ones most likely in crisis, the ones most acutely in need of care, can you get those services to the people? Different questions. And just as far as better services, I'll use an example from my own life. When I was at the height of my psychosis I went through Manhattan for 72 hours with no food, no water, no money, no sleep. Why? Because every other person in Manhattan was a secret agent out to get me. Anybody that tried to help me was a secret agent trying to capture me for these vast superpowers that I had. How was I going to be treated by the availability of more services at that point?

MARGOT ADLER: Michael, you talked about Manhattan. And New York has a law called Kendra's Law, in which the standard for forcing someone into treatment is more loosely defined than imminent danger. In 2005 the New York State Office of Mental Health released the results of a study that said people who were ordered into treatment committed fewer crimes, were less likely to end up homeless or in psychiatric hospitals. Isn't this evidence that the law's working?

MICHAEL ALLEN: I'm not sure that it's evidence because I think that, uh, that report undervalues one of the important things that happened after the passage of Kendra's Law. Advocates all over the state of New York--led principally by Harvey Rosenthal from the New York Association of Psychiatric Rehabilitation Services--convinced the legislature that it would be a cruel joke to put people under court orders where community services didn't exist, and the legislature agreed and came back and funded hundreds of millions of dollars of support of housing, intensive case management, outreach to folks on the streets, so that at the bottom of the OMH report from 1995 we have no real sense of causation. Is it the court order that has led to these increased improved outcomes or is it the enriched and enhanced services that come along with them? There's been a number of studies around the country that say essentially it's the better services that lead to better results; the court order may have little or no effect.

MARGOT ADLER: Jonathan, some critics say that by forcing someone into treatment you'll ultimately turn them off to the mental health system altogether and that the only way for a person to get help effectively is to want that help. You can lead a horse to water but you can't make them drink, or am I wrong?

JONATHAN STANLEY: Well, I'll repeat the result from Kendra's Law. Four out of the five of the people that went through it said it helped them get and stay well. And I'll use my own example in that I was about as psychotic as psychotic get. I don't think I was helping anyone. There was nothing I wanted least, or less, than treatment. I was thrown in a hospital. I stayed there. I got well. I got the medications that took away my symptoms. What did I do? I went back to college. I went to law school and now I work to help people who are like I once was.

MARGOT ADLER: Jonathan, psychology isn't an exact science. It's not uncommon for psychologists to give wrong or conflicting diagnoses. One diagnosis after another, medication doses aren't often given correctly, they have to be monitored and changed: Shouldn't we have a worry about abuses and paternalism when it comes to forced treatment?

JONATHAN STANLEY: Absolutely we should. And that's why commitment is not done by making a phone call and having someone placed in treatment for five months. It's done through a court system with protections. It is done with a lawyer on the side of the person. We have every safeguard that we can put into the system that is necessary. The question is, even given that, psychiatric treatment is not perfect. We reach a point where the question is untreated, out-of-control illness, or the best treatment that we have available.

MARGOT ADLER: Michael, your response to that?

MICHAEL ALLEN: The entire mental health system is based on the idea that helping professionals will connect in a personal way with people who need help to get back to wellness

and that force interrupts that therapeutic relationship. The other difficulty on a policy level is that all this fighting about involuntary outpatient commitment laws, enforced treatment, are essentially stifling innovation. They're draining off the resources that are necessary to fund the programs that have already been proven. And the studies about involuntary outpatient commitment indicate that the jury is still way out on the efficacy of the court order.

MARGOT ADLER: Michael, deinstitutionalization emptied many of the nation's mental hospitals, but now hundreds of thousands of people with mental illness find themselves in jail instead of in hospitals. Isn't that worse? You have just as few rights in jail as in a mental hospital and not much real psychiatric care.

MICHAEL ALLEN: I'm not sure whether I would characterize it as better or worse. Both are institutional settings. Both deprive people of contact with the community, which is fundamentally what helps people to get better. Obviously people have been trans-institutionalized, because the criminal justice system's open 24/7 and essentially mental health is open from 9 to 5. And what we need to do is to inculcate into community mental health the original vision from the 1970s, which was as we close and downsize the institutions, which we recognized to be terrible places, that we invest in keeping the mental health system open around the clock in the same way the criminal justice system is. The appalling thing, apart from these personal outcomes of people with mental illnesses ending up in jail and prison, many of whom I've visited, the more appalling thing is that on a policy level taxpayers are being misinformed. They're being told that mental health is a fairly low percentage of every state's budget, but in fact are paying two and three times the amount to have people institutionalized in settings called jails and prisons. If we could get through to the American taxpayer to understand that preventive and comprehensive services up front are what will keep people with mental illnesses well, we wouldn't be talking about this vast number of people who are ending up in jails and prisons.

MARGOT ADLER: Jonathan, jails or hospitals?

JONATHAN STANLEY: I think what Michael just said shows that he and I will never come to agreement on this subject because I have a very definite opinion of what is better or worse, jails or hospitals, jails or outpatient commitment. And I haven't been in jail but I have been in hospital and if I ever deteriorate again I would far more likely want to be in a mental health facility than in a jail. And part of the reason to intervene quickly is to get people before they get to the point where they end up in jail. Now if one assumes that jail is no better or worse than a hospital, than outpatient commitment, there's no reason to do a commitment whatsoever. We'll just let all people who suffer with mental illness who go into crisis end up in our correctional facilities.

MARGOT ADLER: I'd like to ask both of you: Why is mental illness treated so differently than physical illness? For example, if I have a heart attack or get hit by a car, no one waits for me to OK the treatment. Let's start with you Michael.

MICHAEL ALLEN: We've gotten to this point I think because historically, up until the early 20th century, some of the theories about mental illness had to do with demons and with superstition. There's still a deep stigma against people with mental illnesses and until very

recently it's been difficult for virtually anybody to admit that they or a family member has a mental illness. So we've been in the closet and our folks have been in the closet and have felt very uneasy about talking about these sorts of issues. As a consequence we have laws that--in terms of insurance--that historically have treated mental and physical illnesses entirely differently, capping and disqualifying mental illness treatment in a way that would never happen in terms of physical illnesses. But on the treatment side, fundamentally we have the right to choose our own medical care and our own mental health care. The question of overcoming somebody's will--we would never tell a cancer patient that she was required to take the treatment that a doctor said. We would never tell someone with diabetes that we know better than you. In this particular instance we've got to move to a place where mental and physical illnesses are seen in the same kind of way and where the right to choose or to refuse treatment are honored in both.

MARGOT ADLER: Jonathan?

JONATHAN STANLEY: There is no rational reason why the effects of mental illness should be treated differently than physical disorders. But yet it's there. And that's what we work for with treatment law reform is to get an equivalent treatment for mental illness. And just to give an example, I once talked to a doctor at a hospital who was in charge of people who were incompetent to consent to physical treatment. And he told me that I can go through the court process and I can be empowered under the standard, which was basically to make rational decisions considering your welfare to order heart surgery, to order an amputation, but even then I cannot order an anti-psychotic for the person.

MARGOT ADLER: Thank you both for talking with me today.

MICHAEL ALLEN: Thank you, Margot.

JONATHAN STANLEY: Thank you.

MARGOT ADLER: Jonathan Stanley is the acting executive director of the Treatment Advocacy Center. Michael Allen is a lawyer specializing in housing and civil rights issues with the firm of Relman & Dane.

To see what the law in your state says about forced treatment, go to our website, justicetalking.org.

MARGOT ADLER: Elyn Saks, who is schizophrenic, has her own take on involuntary treatment, both as a legal scholar and also from firsthand experience.

ELYN SAKS: I was treated originally in England, which uses much less coercion than America does. But when I came back to America I had a very public breakdown on the roof of the Yale Law School and I was brought to the emergency room. And I received in the next few weeks three forms of forced treatment. First, I was involuntarily hospitalized. Second, I was involuntarily medicated. And third, I was restrained. I was said to be dangerous to myself and

others, and also gravely disabled because I could not do my Yale Law School homework. And I wondered what that meant for most of the rest of New Haven: If they couldn't do my Yale Law School homework, were they committable? And I was forcibly medicated, but I learned quickly that, you know, no point to refusing, they are just going to medicate you. So I might as well take it orally. And then I was restrained. And the first two or three days, or the first two days, I was restrained most of the time those two days. And then for the next three weeks I was restrained anywhere from an hour to five to eight hours a day. And I can't describe how horrible an experience it was for me. It's degrading. It's humiliating. It makes you feel totally helpless. And finally, after about 10 to 12 hours, it's extremely painful. I mean try not to move even an inch. It really starts hurting. And you don't know when it's going to end. So for me it was a terrible experience and I had nightmares many years afterwards.

MARGOT ADLER: I asked her if she thought if any of the times she was treated without her consent were justifiable.

ELYN SAKS: I don't think any of the treatment was below the standard of care. I think it was reasonable. I think it was wrong. I think it made me worse. But I don't think it was, uh, you know, negligent or anything like that. I don't think I was really violent, but it was okay, reasonable to think I was. I was certainly saying scary things.

MARGOT ADLER: Later in the show, more of my conversation with University of Southern California law professor Elyn Saks. She talks about how she copes with bouts of madness and leads a successful, productive life despite her schizophrenia. We'll also hear about the unthinkable choice thousands of parents have to face giving up custody of a mentally ill child in order to get the child treatment. Stay with us.

MARGOT ADLER: This is Justice Talking, where we make the connection between law and American life. I'm Margot Adler. Millions of families have to deal with a family member who has severe mental illness. This can be particularly painful when it comes to children. Marie, who lives in Ohio, struggled for years to get adequate care for her son, who suffers from bipolar disorder. They tried different medications and treatments, including numerous hospitalizations, some for months at a time. The financial burden finally overwhelmed them and Marie and her husband faced a difficult decision.

MARIE: After the several years of paying co-pays and whatnot, we'd maxed out on our insurance and we were at this point pretty financially strapped and couldn't afford this last round of treatment that they were recommending. So there was a social worker who actually came to the house and was talking to us and she just said well have you ever thought about giving up custody and we were like no. Obviously we had never thought about that. And she said if we would do that that we would turn our son over to the state and they would provide the treatment that he needed. We made the decision. He was 16 at the time. We made the decision to go ahead and turn over custody so that he could get the treatment that he needed. And he remained in treatment until his 18th birthday. When you've made the decision to give up custody there's a push to get rid of the mental health stigma in the world but it's not. It's still

very much there. So you're feeling a lot like you're doing this alone. You can't tell, you know, your friends at church, because you'll feel like you'll be judged. We had difficulty even with our own family understanding, you know, how we could do such a thing. And even now, when our son is an adult, we look back on it and feel that we made the right decision. He has actually thanked us for what we did for him. So it validated that, you know, we were correct in our decision.

MARGOT ADLER: Marie is hardly alone in making the tough decision to give up her parental rights so that her son could get the treatment he needed. More than 12,000 families give up custody of their children each year for the same reason. In fact, the numbers are probably much higher because big states like California and Texas don't track how often this happens.

Darcy Gruttadaro is a lawyer with the National Alliance on Mental Illness. She's worked extensively on mental illness and custody issues. Darcy, why are parents having to face this kind of a choice?

DARCY GRUTTADARO: It primarily happens with middle-income families who have private health insurance plans and don't qualify for Medicaid coverage and their private insurance plans have restrictive and discriminatory caps on mental health coverage. And it typically occurs with children in adolescence that have severe and serious mental health treatment needs. They've exhausted their private insurance coverage. They don't qualify for Medicaid and they go to state officials to ask for help. And what typically happens is state officials notify them that in order for the state to provide services, the family will have to give up legal custody of their child to, typically, the child welfare system, where they can get the care that they need. But the child must be in state custody.

MARGOT ADLER: You'd have to be at a point of total desperation to give up your parental rights, I would think.

DARCY GRUTTADARO: Yes. I think that characterizes it extremely well. These are families that have really tried everything imaginable and they typically have a child that has such intensive needs that it's impacting siblings. It's impacting the ability of the parent to keep the child with the mental illness safe. And sometimes it even includes the inability to keep those around them safe. So parents are very desperate and they're quite surprised and shocked to learn that this is the only option they have. We hear that over and over again from families that contact us from around the country.

MARGOT ADLER: And if they hear from the state that this is the only option-- First of all, is it the only option?

DARCY GRUTTADARO: It is, because of the funding mechanisms that are available for services. So when the state is looking at what their options are they're looking at where do we have a pool of money that can help us provide services for their child. Another troubling aspect of the custody relinquishment issue is that families are forced, when their child is given up-- when they've given up custody of their child to the Child Welfare System, to work with case workers in the Child Welfare System whose orientation it is to work with families that have been

involved in abuse and neglect. And the troubling aspect to this is that families are often treated no differently than those families that are involved in abuse and neglect. So loving parents who have done everything to get mental health services for their child are treated no differently than parents involved in abuse and neglect cases. And this is very, very difficult, as you can well imagine, for families.

MARGOT ADLER: What happens to these kids? Do they end up in foster care? Do their parents get them back? Do the parents have any say in what happens to their kids?

DARCY GRUTTADARO: What typically happens is many of these children end up going into residential treatment centers, and sometimes those residential centers are in their communities and sometimes these children are sent out of state. And in many cases the families lose legal custody of the child so they lose the right to make day-to-day decisions about the child's treatment, about medication, about their religion, about the day-to-day life decisions that impact children and that families typically are involved in. So it's very problematic. Some families we've talked with over the years have actually gotten legal custody back of their child when the child gets a little bit older. But as you can imagine, this is a very difficult thing for families to go through.

MARGOT ADLER: And I would imagine that the children are also completely devastated.

DARCY GRUTTADARO: They are completely devastated. And they, their parents, have to explain to them there is no other way to get them treatment. It doesn't just devastate the children who are taken away from their families in their hour of greatest need, but it also impacts siblings and those children who remain at home and see their sibling leave and know that their parents have given up legal custody.

MARGOT ADLER: A couple of years ago there was legislation introduced in Congress called the Keeping Families Together Act. The bill promised to end the practice of child custody relinquishment. What would this legislation do and what's its status now?

DARCY GRUTTADARO: The bill has strong bipartisan support in both the Senate and the House and we're extremely hopeful that it will pass eventually. There seems to be a great amount of interest on the part of federal lawmakers in this issue. Unfortunately, it's hard to keep it on the front burner with all the other political issues that are being addressed in Congress.

MARGOT ADLER: As you look at these families and look at these issues, what do you see as the solution to this problem?

DARCY GRUTTADARO: Really just investing in a mental health system in this nation that addresses the needs of children and adolescents. What often happens is we wait until we have a crisis situation and then it's far more costly, instead of identifying children and adolescents early with mental health needs, particularly serious mental health needs, and getting them the care that they need so that they can continue to participate in school, to live in the community, to have friends, and to do well.

MARGOT ADLER: We've been talking about the situation where kids are mentally ill. But let's talk for a minute about what happens when a parent is mentally ill. Sometimes kids are taken away from their parents if the parents exhibit mental illness. What does the law say about that?

DARCY GRUTTADARO: I think the important issue to bear in mind is that when adults that have mental illness are in treatment, many of them can lead relatively ordinary lives. There are certainly exceptions with some serious mental illnesses that may be treatment-resistant, but many people that have mental illnesses lead very quote-unquote "normal" lives. They have jobs. They are parents. They participate in their communities. They can be very stable with treatment. Unfortunately, there continues to be a tremendous amount of misinformation about what it means to have a mental illness. So we hear from parents that indicate that in, for example, divorce proceedings, one spouse will use the existence of the mental illness against another spouse to gain custody of a child or to prohibit the other parent from having custody of a child. And again, there's a lot of stigma and misunderstanding about what it means to have a mental illness. And often in these kinds of custody cases the standard is what's in "the best interest of the child." So there's a tremendous amount of discretion left to judges. And in those cases we remain concerned that many judges aren't well educated about the fact that people can live fairly normal lives with mental illnesses.

MARGOT ADLER: Darcy Gruttadaro is a lawyer with the National Alliance on Mental Illness. Thank you for talking with me.

DARCY GRUTTADARO: Thank you. It's been a pleasure.

MARGOT ADLER: There are a number of successful people who have talked openly about dealing with severe depression, but when it comes to schizophrenia, there are very few role models. That was part of why Elyn Saks decided to go public about her struggles with the illness. Her new memoir is called "The Center Cannot Hold: My Journey Through Madness." She is a law professor at the University of Southern California. I asked Elyn to talk about how she has managed to have such a successful life. When did you realize you had a mental illness and what was the beginning like?

ELYN SAKS: I've been very, very fortunate, and I think the things that really helped me were psychoanalytic treatments, psychoanalytic psychotherapy. People like me are not supposed to benefit from it, but for me it's been one of the key parts of my recovery, and if I didn't have it I'm afraid I would've enacted the grave prognosis that I was given. The second thing is I'm a good responder to medication. I don't respond to all antipsychotics--I've tried different ones that haven't worked--but there are some that work very, very well. And very, very supportive friends and family. I have a great husband who is very sensitive to how I'm doing. And I love to work, which really stands me in good stead because it gives me a focus. It gives me a way to be productive. It's just, again, another essential part of my recovery. And finally, coming to terms with the fact that I have this and that I need the treatment, and, you know, stop struggling so hard against it, fighting against it, which ended up meaning I spent a lot of time doing that and less time doing the other joyful, wonderful things that one can do with one's life.

MARGOT ADLER: So I guess my question is: When did you realize you had a mental illness and what was the beginning like?

ELYN SAKS: I guess I had kind of early warning signs as a little girl: extreme fearfulness, phobias, obsessions, felt like a man was standing outside my window ready to break in, had some periods of disorganization, and ended up having kind of, frankly, a psychotic episode, where I thought houses were talking to me. But I didn't really formally break down until I got to Oxford, England in 1977, and I broke down and I was hospitalized. And then I was in treatment. And then I went back to America and broke down and was involuntarily hospitalized and involuntarily treated for years. And then I got into analysis again. And it probably took even after my first break in Oxford another 20 years before I could actually say the words "I have a mental illness." I have schizophrenia and I need medication and psychotherapy and I will for the rest of my life. And for all those years--I mean, I was a relatively intelligent person, relatively high-functioning--I simply assumed that other people thought that little beings were in their brains setting off nuclear explosions, or that they had killed hundreds of thousands of peoples with their thoughts but they just didn't say it because it was socially inappropriate. So I was socially maladroit but not mentally ill. And there are several things that happened that brought me finally to accept that, but it took a long time. It was a hard fought battle.

MARGOT ADLER: When did you make peace with your condition?

ELYN SAKS: I would say it was probably about 10 years ago when I got on this new medication and started really feeling better. And I used to say I don't want to take medication because I don't want a crutch. And then I thought to myself if I had a broken ankle I'd use a crutch. My neurotransmitters are broken. Why wouldn't I use as much a crutch for them as for anything else? And I made my peace with it and I am at peace with it. And it makes my life go much better. So whether it's ultimately true in the grand scheme of things, it serves kind of my well-being and my mental health to accept that I have an illness. And paradoxically, once I accepted I had it, it defined me much less.

MARGOT ADLER: Hmm.

ELYN SAKS: It became kind of accident instead of essence.

MARGOT ADLER: One of the more amazing parts of your book is when you finally get your diagnosis. Of course you got different diagnoses through the years.

ELYN SAKS: Right, right.

MARGOT ADLER: But talk about that. Describe what happened, what your diagnosis was, and how you reacted when you first heard that?

ELYN SAKS: As you said, I was given different diagnoses. When I first became ill I looked like I was psychotically depressed, but over time it evolved into more of what they call a thought disorder than a mood disorder. I don't really have too many extreme mood swings. But I do get

disorganized and I do have delusions and hallucinations. I knew schizophrenia was a damning diagnosis and it was very upsetting to hear it. I was not explicitly told you have a grave prognosis. I read that later. But I was told that I probably should scale down my expectations and that kind of thing. My brother, one of my brothers, Warren, has always said I was very stubborn. And I kind of stubbornly refused to admit that I was going to have a scaled-down life.

MARGOT ADLER: And you don't.

ELYN SAKS: And I don't. I don't. I've ended up having a very good life. I've been very fortunate.

MARGOT ADLER: Your book is a kind of coming-out-of-the-closet about your illness.

ELYN SAKS: Absolutely.

MARGOT ADLER: Why did you decide to do that?

ELYN SAKS: You know, I thought about it for a long, long time and for a long time I thought I wouldn't do it. And it just gradually dawned on me that this could be a very important and helpful thing to do for people. A psychiatric friend of mine, a psychiatrist friend of mine, when I told her the story, was a bit taken aback. She said gosh, I would never have known. She said don't you want to do it under a pseudonym? And I said, well, you know, I thought that would send the wrong message, that's it's too awful to say out loud. And she said, well, but do you want to become known essentially as a schizophrenic with a job? And I was really taken aback and I thought well, no, I don't. And I want people to read my work, you know, without prejudice and that kind of thing, and see it for what it's worth. But then I thought, you know, I probably I could never write anything academic that might help as many people as this. And I was willing, I was willing to do it. Maybe I was also just tired of having a secret. It's a burden. People with schizophrenia read the newspapers and we see how we're portrayed. And it's, you know, you tell at great risk.

MARGOT ADLER: As we've said, you know, you lead this very productive life. Do you have certain strategies to sort of deal with your illness when you feel it's coming on now or something like that? Are there things that you do?

ELYN SAKS: Yeah. I'm very aware of my early warning signs and when things start looking problematic I note that to myself and I talk to my psychiatrist and my analyst. I have a lot of people in my environment who are very sensitive to how I'm doing who may sometimes be able to tell before I can that things aren't going well. I've been fortunate, even when I'm seriously ill, and even when I believe what I think is true, to usually have a good sense of what other people are going to think is crazy, and so I don't say it if I can. I can't control what I think, but I can mostly control what I say. And if I feel like I'm so pressured to say it, I know to just stay home and, you know, kind of listen to music, talk to friends, and try to get myself back together before going out into the world again and, you know, doing what I do. So I think it's those things. I think it's having people around me who know. I think it's having therapists who I can turn to

and talk to about what I'm afraid of and what I'm feeling and fearing. And the understanding so that I'm socially appropriate.

MARGOT ADLER: Elyn Saks' memoir, "The Center Cannot Hold: My Journey Through Madness," has just been published. She's a law professor at the University of Southern California. She is also completing her doctoral thesis in psychoanalysis.

MARGOT ADLER: To hear more of my conversation with Elyn Saks, go to our website, justicetalking.org.

While there, you can post on our message boards, learn more about our guests, and sign up for our free podcast. And check out our blog, where many of the nation's leading commentators give their views on law and American life. Thanks for listening. I hope you'll tune in next week. I'm Margot Adler.
