Host intro: In his early 20s, Mindy Greiling’s son, Jim, was diagnosed with schizoaffective disorder. At the time, and for more than a decade after, Greiling was a Minnesota state legislator who struggled along with her husband to navigate and improve the state’s inadequate mental health system. Her book, *Fix What You Can*, is an illuminating and frank account of caring for a person with mental illness told by a parent and advocate. Greiling is joined here today by Minnesota Public Radio’s mental health reporter, Alisa Roth, author of *Insane: America’s Criminal Treatment of Mental Illness*. This edited conversation was recorded in August 2020.

Mindy Greiling: This is Mindy Greiling, and I’m really happy to be here this afternoon with Alisa Roth. I, myself, have a son who has schizoaffective disorder, and we have noticed over the last 20 years that we intersect with the criminal justice system a lot. So, a couple of years ago, I got to go to a conference at Hamline University where Alisa Roth was the keynote speaker, and she featured her newly released book, *Insane: America’s Criminal Treatment of Mental Illness*. I had noticed both with my son, who has schizoaffective disorder, and with my grandmother, who long ago had schizophrenia and was in the Rochester State Hospital, that the sheriff got involved or sometimes the police. But I never really put it together that the people who are in prisons and jails today are not the very same people — as a lot of mental health professionals claim — as those who were in the state hospital, like my grandmother in the ’50s. And Alisa, what I wanted to ask you is: Could you tell us what you found when you researched these two different populations?

Alisa Roth: Absolutely. This is Alisa Roth. And Mindy, it’s great to talk to you again. It's interesting, when we look at the history of the criminal justice system and of our mental health system, there is a distraction and a confusion, which is this: In the 1950s and the 1960s, we shut down huge numbers of psychiatric hospitals across the country and released huge numbers of psychiatric patients to the community. Roughly the same time, we began the war on drugs, and the number of people in our jails and prisons started going up, exponentially. And so, when you look at just the numbers, without looking at who’s there, it’s easy to think that: “Oh, we took all those people out of the hospitals, and we sent them into our jails and prisons, and that’s where they've ended up. Boom. End of story.” But when you dig a little bit deeper, and you look at who was in the
hospital back in the day, and who are in our jails and prisons now, we see that it's very different populations. It sounds like your grandmother was really typical of that population that was in the state hospitals in the first half of the last century: largely elderly, white and female, and largely diagnosed with schizophrenia. When we look at our population in jails and prisons today, we know that the vast majority of people are young, not white, male. When we look at the diagnoses among people in jails and prisons [today], it's really much more reflective of what we see in greater society. So, it's not just schizophrenia, but it's major depression, bipolar disorder and a range of other diagnoses. Mindy, one of the things that really struck me in reading your book is the involvement of the police. I've heard these stories over and over from parents all over the country, from family members. If your child or your loved one needs care, needs hospitalization, the quickest and easiest, and in many cases, the only way to get this care is to call 9-1-1 and ask the police to get involved. In reading your book and your story, what struck me was not just that this is the case, but that this is the case for a family like yours. Here's a family that has the insurance, that has the knowledge, has the connections, knows who to call. If a state legislator can't get her child taken care of without calling 9-1-1, what is wrong with this system?

MG: Well, that is the $64,000-question. I just felt so privileged to be a legislator the whole time our son was getting sick and all along, as we went through the mental health system. But yet, with all our privilege being a white person, like you said, with insurance, powerful in the Legislature, still, this was the best we could do. So, I worry always throughout my book, what about everybody else and people that are afraid of the police and afraid of doctors and so forth? We have a long ways to go, because when I first started this book's story, it was 20 years ago. But this still happens to our family nowadays. I have called the crisis team as recently as less than two years ago, and I still get that answer. If the person isn't willing to accept going to the hospital, even though they're very sick but don't recognize it, the crisis team wants families to call 9-1-1 and get police backup. They don't want to come out and deal with dangerous or volatile situations, either. And that to me is heartbreaking. Oftentimes, the person isn't even dangerous at all. We all know that's a misnomer to think that people with mental illness are always dangerous. They’re just very, very sick. And the crisis workers still would rather come with the police involvement. And also, the police can get here faster. The crisis teams aren't operating 24/7 and can't come and get the traffic lights to turn white and so forth. There's just many factors. But I think this is why we have such a criminalized mental health system, because once the police come, it's a whole new ballgame.

AR: Tell me about the last time that you called that crisis team. At what point did they say you may need to call the police?
MG: Well, actually, I’d been working with the case manager and the case manager’s boss through **People [Incorporated]**, where our son gets all of his services. And just like me, they’re a very privileged organization. You know, they’re the largest game in town, in probably the state, certainly the metro area, and they’re very sophisticated. But because we have **person-centered care** — which is a really good thing most of the time, but not when someone doesn’t recognize they’re ill, and they’re in crisis — their hands are tied if the person isn’t willing to go to the emergency room when they need help or to accept recommendations that would help them be better. So, the last time, they recommended that I try the crisis team, and they also had tried it themselves or tried to pave the way. But between them and me, my answer still was that there really wasn't anything they could do if Jim wasn't willing to accept help. And he was also using substances at that time that exacerbated his mental illness. So, they just recommended that if it came to a crisis where — and families like mine are very sophisticated as to when you can call the police or when they might be able to do something — that would be what we should do, call the police. And I actually did that a couple of times. And once, the police weren’t even of any help because they had had some training, and the training told them that someone with the illness that my son has, schizoaffective disorder, that they always were acting like that. At the time, Jim was very, very sick. He thought people were talking about him. We were in a coffee shop. I was trying to figure out where he could be safe, and that’s where he wanted to go. So, I followed him along, and he was actually spitting towards other patrons because he thought they were saying hateful things. And the police said: “Well, that was normal behavior,” and there wasn’t anything they could do. So, it’s very complicated for parents, even with police involvement. Another recent time, we called because Jim was just out of control at our house, also because of his substance abuse that makes this mental illness worse. And the police came, and what they ended up doing was taking him back to another location away from our house. But in neither case did he end up at the hospital. A third time, very recently, he thought he had been robbed at a gas station. He called the police himself, and they came and we came because he called us (my husband and I) and met him at a gas station in St. Paul. And there again, they assessed that he must be not doing well because he actually hadn't been robbed. His keys and his things that he thought were missing were somehow in the backseat of his car. But they just left him there, left us with him. So, you know, it’s very hard. If he then got sicker and committed some petty crime, he could easily get to jail.

AR: Well, that's the irony, right, that it's much easier to get into jail than it is into the hospital. I’m curious, you talk about being white, which, of course, changes the dynamic with the police. But were you ever afraid for Jim's life and well-being when you called the police? As you know, it's something like **1 in 4 police shootings involve a person with mental illness**.
MG: Yes. And I think I also read that more than half of those police shootings are people of color. But even so, I still take my heart in my throat when you call the police because anything can happen. And, of course, they have guns, so anything can go wrong. I am sure I don't have the same terrible feeling that a person of color would have. I'm positive I have a privilege in that regard, but I'm still terrified to call them because you never know what could happen.

AR: People like to look at the situation we're in and say that our jails and prisons have become our mental health system. And in some ways, that is correct. The criminal justice system has become our de facto mental health system, and we can talk more about people going to jail. And that's the place they're getting diagnosed or going to prison, and that's the place they're getting their mental health care. So, I think we need to think about who's ending up in the jails and prisons now, and what does that say about how we are treating people with mental illness? I think it's interesting, now, as we are talking about race in the criminal justice system, it's important to note that even if somebody like your son has ended up involved in the criminal justice system in some way, he's not spending tremendous amounts of time in jail, in prison. He's coming in and out of it. And this is absolutely a problem. And again, something we could talk about more. But the vast majority of the people who are ending up in the criminal justice system are not people like your son.

MG: I think that's right. And that's another point of my book — advocacy. I have all the levers I can push. I know what they are. I know all my elected officials. I'm very assertive about raising the roof when I need to. And so, that's one thing I wanted to showcase in my book was how that can look for all families if they work with elected officials — which, a lot of people don't even know they can if they're in trouble trying to navigate the mental health system — and then to educate yourselves through NAMI: National Alliance on Mental Illness. You know, knowledge is power. And I think a lot of the mental health organizations, traditionally, have served people who are the majority culture, white people; now, we have so many more people of color who need the mental health system. And I think the organizations are making that pivot now very nicely, but need to continue doing that because it's the ones who don't get help who end up being stuck in jail or end up in the prisons. Our son had a chance to go to mental health court, for instance, the first time he got in trouble with the law. He was driving his car too fast, and he hit another car and got charged with criminal vehicular operation. And we were so pleased that he got into mental health court. The second time, later on in our lives, he had another situation where he didn't get into mental health court. So, we got to see the criminal side of the court and how different that is. It's not geared for rehabilitation in any way, shape or form. But he still ended up with probation, not having to be in jail or prison. And my heart
breaks for people that don't have the savvy that our family does, which is one of the many reasons that I wrote the book.

**AR:** You know, one of the things that I find so shocking is that even if we remove the criminal justice piece from it, you had so much trouble getting access to care for Jim. I even remember the first time that we talked one-on-one about this. I met you and Jim, and he was waiting to get into a residency that would be his sort of interim step. It seemed to me, again, over and over reading your book, that of all the people who should be able to find their way through the system and be able to see the psychologist, I think you talked about it being months, you were once directed to a psychiatrist and it was going to be weeks or months before you could get in. How is it that you were unable, knowing all the right people to talk to, all the the right places to go to, even understanding how to navigate the system or who could tell you how to navigate the system, that you couldn't get him into the care faster and get him into the care that you were hoping for, for him.

**MG:** Well, I think that's the problem — even somebody that knows as much as I do and has the privilege that I do, this is as good as the mental health system can be. When I first started complaining about things and mentioned how many weeks it took for Jim to see his first psychiatrist, the people in the mental health system, I remember distinctly, a lobbyist — from, at the time, it was called the Mental Health Association, now it's [Mental Health Minnesota](http://www.mhmn.org) — said: “Well, that's better than most people.” And so, we did get some privilege, I guess. But you could fool me because it didn't feel like it. It's very, very slow. And other people have to wait even longer. Once Jim had had a recent suicide attempt, and he was in the hospital and they just kept him for a few days and they were ready to dismiss him because he no longer met the criteria to be there without his willingness. And they call that in Minnesota “treat to street.” You get treated till you're good enough to put out on the street. And that time, I did have a lot of privilege because I called [NAMI Minnesota](https://www.nami.org/). I called the state ombudsman for mental health, then also called my legislators, the county commissioner, the commissioner of health and human services got involved. And Jim was rescued from having to go to the street and went from the hospital to something like, almost two years' worth of being shuffled from one mental health facility to another until we found a place for him to live. So, that time, which seemed awful to us, I think when I met with you, was one of the times he was waiting for somewhere to go. That's the best the mental health system gets. There's just not enough capacity. People can't get care when they need it. We know what should be done, but we just don't have enough of it. And then, those who have privilege or power or who rattle the cages might make it in; maybe other people might make it in. But the vast majority are left with their sickness out on the street. And no wonder then, if they're hungry and they shoplift something to eat, they end up
in the criminal system, or their illness gets so bad that they do something even worse, and then, they end up in prison. The name of your book, *Insane*, is exactly how I feel about our mental health system.

**AR:** Every time I look at this, I think, how can we possibly fix it and where did it go wrong? And one of the things that I think is interesting about Minnesota is that it's better than a lot of places, and it's still not very good. And when you look at these mental health organizations, I'm sure you've seen these where they come out once a year rating states on their mental health care systems. And it seems like nobody ever gets above a C-. But if you, as somebody who's both been involved in putting together legislation for the state in terms of how it deals with mental health and mental illness, and as somebody who's lived here for a long time and obviously, paid attention to these issues, if you had to point to one thing or two things that are the Achilles' heel — where the state messed up or what the state needs to fix — what would those be?

**MG:** Well, one of them is long-term, sustained care. We're better at crisis care. If somebody is in huge crisis, they meet the criteria, the hospitals take them in. Then, we paste people together, and that's the best thing that we do. But if someone needs longer-term care, then we have what I call a medium-level care that's over really fast. A lot of our care after the hospital — the step-down programs — are 90 days (three months), and we have intensive, residential treatment services and such. And they're all 90 days. Well, hello: Something like schizophrenia is not going to be cured in 90 days. It's not even going to be managed in 90 days. But if you manage to get in the hospital, and you manage to get into a 90-day program, you're still going to be kicked out onto the street at the end as if you are cured — or, when the insurance money runs out. There's all these artificial things to say you're done, and nobody's done with a serious mental illness. And that's, I think, the worst part of it. The other part that enters in, that we haven't got a handle on is the fact that some people who could get help don't accept it because they don't recognize their illness. It's of course, it's the brain that's ill and that's not thinking clearly. And if you think you don't have a mental illness, and you are very, very sick, that can often cause you to deteriorate to the point where you could end up in a criminal situation. And the [state mental health] ombudsman, Roberta Opheim, I've heard her say that it's really a gray area, the person-centered care. I've talked about it with my state senator now that I'm out of the Legislature, and my state representative — that is, person-centered care. I think that we need to work harder for those few people who don't recognize that they're ill, who are seriously ill — and often [their condition is] compounded by substance abuse — we need to step in earlier. And this year, in the Legislature, I followed the earlier intervention legislation put forward by NAMI Minnesota. I had a chance to read their earlier versions, and I said I could tell it was written by a committee because it didn't do as much to begin with as I
would like it to do. But one part that I did like about it was a part called, I think it was a sort of [term around] “engagement” or something like that. [It’s] where mental health crisis teams could work with people who were seriously ill, skating close to the edge to need civil commitment, but to head it off ahead of time. And get people earlier help — to be really assertive and in-their-faces, trying to get them to accept care and not have to lose all their rights and be civilly committed. And thankfully, the Legislature passed it. Unthankfully, my reading of the summary was it's a county option. Well, something that's a county option, I know from my 20 years in the Legislature, that's the weakest thing you could do, especially in the middle of COVID-19, health care budgets. Something that's a county option is probably unlikely to be started anytime soon. And if it is, it might be in Ramsey [County] or Hennepin [County]. We have three mental health courts in our state out of 87 counties, and they're only in Ramsey, Hennepin and St. Louis County (up with Duluth). So, all the other counties, there's a lot of people that live there too, and people who are seriously ill are not headed off at the pass. They are often apt to end up in the criminal justice system. I think those two things — we don't have sustained help for people. We just try to patch them together and hope that they'll be fine after that, or we don't intervene and help people who don't recognize their illness. And those are the very ones often who end up in the criminal justice system.

**AR:** Of course, they both come back to this lack of a system or as many people I've talked to say: “We don't have a system — to call it a ‘mental health system’ is giving it way too much credit.” I think it's interesting on the early intervention question, it feels like this is part of the problem, that we don't have enough care. Because I've talked to so many people — and not just in Minnesota — really, all over the country who say: “You know, my child or my loved one or I, myself, was experiencing symptoms very early.” And we know from the medical, the scientific research that the early intervention really helps head off the need for more serious interventions. But if you can't get that person in to see a provider and to start getting that care, then you can't intervene early. And so, it becomes a cycle. And then, on the longer-term care, we can't fit the person into where they need to be and where should they go, and who should pay for it — when we're talking about people who don't recognize that they're sick, who have gotten to a point where they can't see the need for treatment. Of course, part of our reluctance to intervene is the need to respect people's civil rights and human rights, and to be able to say: “Your child is an adult, he doesn't want his parents necessarily telling him what to do,” even if there are times when his parents need to be telling him what to do. What's your take as a parent on all of this, whether it's you being able to tell your adult child: “You know what, you need to go to the doctor and get care, or, you need to be taking your medications,” or, if it's you wanting to get information from the doctor where they're saying: “We can't tell you that because this patient is an adult.” What's your take on that?
MG: Those are all big problems, and the interesting thing is, our son, 95% of the time has signed the medical releases for people to talk to us if he’s asked. And still, we get treated as if he hadn’t signed them because the mental health system, the professionals are so much into the thinking that people with mental illness don’t want their families involved. Or maybe it’s because that takes more time. But when presented with releases, our son actually signs them, and we are not blocked in that regard as much as we are just with the thinking of the mental health system, because he’s an adult, because he's not 16. And so, I think there could be a lot more within the mental health system with the providers just assuming that family should be involved and assuming people will sign the releases if they just said: “Here's all the things you need to sign so we can talk to your social worker or your case manager and your parents and your other doctors.” I think more people would just sign them automatically. But when you get to the one about parents, providers often will hold that one up or wait, [saying:] “This one is your family. Do you want us talking to them?” I think there’s some of that that goes on, a lot of that, and that gets in the way of communication. One of the bills I worked on in the Legislature was to move the age from 16 to 17 when families could still be involved without having to bother with releases. In other words, until a child turned 18, families could be involved. I actually had a police officer who came and asked that I work on that legislation because he worked with runaway teenagers who he knew had mental illnesses, chemical dependencies, and families that had 16-, 17-year-olds couldn't even communicate [with their children] without having releases signed. So, I think we've gone a little too far in assuming people don't want their families involved. There's research that shows that people whose families are involved do better. That's just one of the evidence-based practices that is highly touted. And I think it's a mindset that needs a lot of work in the mental health system.

AR: It's one more way where we see this strange division between how we treat mental health and how we treat physical health — where, of course, you still need to sign the papers to allow your family to know that you're being treated for cancer or that you were in a car accident or whatever it is. But at the same time, I think that the medical establishment is so much more willing to engage the family and encouraging patients to engage the family when it comes to physical health needs. But somehow, when it comes to mental health, we've turned it into this big, secret thing with the wall where it's not good for the family to be involved, or it's too much trouble, or we're worried about the patient not really wanting that. And I think, as you say, that it really does affect how people do. And of course, there are cases where the family is not helping the problem and is maybe hindering things. And of course, the providers need to be aware of that. But as a general practice, it seems like if we made it easier at least to get the families involved, that people would be the better for it. I want to ask you, too,
about — you talk about the need for long-term care for people. And I think here again, we fear returning to those bad, old days of the institutions like where your grandmother was taken care of, if we can call it that. What do you imagine as the ideal scenario? You look at Jim — where should he [be], given his circumstances; what is your ideal scenario for a place that he could get long-term care and where he would want to get long-term care?

**MG:** I love the concept of supportive housing. Right now, Jim does have a very nice apartment in Minneapolis, but he's in with all people who go to work every day, and people are ships passing in the night. There's no staff there if anything should happen. So, he's at our house a lot because especially now, when coffee shops aren't open that he likes to go to and so forth. At one time, he was in a program where there were four to eight people in what they call the lodge. And then everybody worked and shared making meals and the housekeeping, and they had built-in friends. Often, people with serious mental illness lose their friends, and [having friends is] an important part of being healthy. So, I'm really big on having the supportive housing. I like the smaller groups of housing, but we do a really good job with people with developmental disabilities where they have group homes and things. And people with mental illness often are more independent. There's foster care. I'm not a fan of that, where people get money to take people in and make sure they take their meds and food. It's better than being on the street, don't get me wrong, but I like to honor and respect people that have a lot of ability still. So, to have places where it wouldn't be a large place, maybe 30 units, and everybody had a common family room or recreation center, but yet, everyone had their own bedrooms, and then, staff would be on-site. I think that would be a very respectful and healthy way for people with schizophrenia. There are the Board & Care that can be really big. And Jim was in one of those one time. He got really good medical care; it was clean and neat and good food, but people were just so packed in there that it was not anyplace he wanted to be. But I think we could invent things. I love the model where we were once in a CSA, where a small number of people with developmental disabilities lived on a farm, and then, they planted the vegetables and washed them up and got them to market. And they always had staff. They lived there [on the farm] year-round as their permanent residence. I don't think we think enough about what kind of permanent home people with things like schizophrenia can have. And I don't advocate for people living with their families because parents are going to die before the person does most of the time. And I think it's just a healthier relationship if parents can be parents, and then, the person with mental illness can come and visit or that sort of thing. That's one thing I don't like about this mental health system — when everything else goes wrong, the person is back with the parents. You know, they often say: 'You don't have a release, we can't talk to you, stay away. We're handling this.' And then, when everything goes wrong, the parents are left holding the bag, anyway. That's the kind of thing that gets very
frustrating for me. So, I would like to ask one question of you, if that's alright. I just so appreciated reading your book and learning so much about connecting the dots with the criminalization of mental illness. And I'm so pleased; I saw, I think, on Twitter that you are now doing a fellowship next year with the Rosalynn Carter Mental Health Journalism Fellowship. And so, I'm honored to be on this program with someone like you. And I'm so grateful for your extraordinary work in the public sector. But from having worked on not having the mental health system criminalized — that was your conclusions, of course — what are the one or two things you would recommend to stop this pipeline of people with mental illness ending up in prisons and jails?

**AR:** Well, thank you so much for the very, very kind words. I think we can look at both systems, if we can call it that, and see things that should be changed. A major, major change on the criminal justice side is that we just lock up way too many people. And I think it's one of the silver linings. I hate talking about the silver linings of the COVID-19 crisis because it's so awful. But I do think that it has at least gotten people to think about, do these people really need to be locked up? And I think that there are a lot of ways that you can not lock people up or not keep people in jail or prison once they are locked up. But I think that once we start reducing the number of people who are tangled up in the criminal justice system, whatever piece of it, that will help keep the people with mental illness out of the system. We also need to remember that as long as we have people in the jails and prisons, we need to make sure that they're getting the care that they need. They are constitutionally guaranteed health care, including mental health care. But all too often, what that health care looks like and what that mental health care, in particular, looks like is really not what it should be. I think on the mental health side, it's a lot of what we talked about — it's really generous to call it a system. It is such a patchwork of care. I often look at it, and I think I'm somebody who's pretty educated. My career has been digging out information about things. And if, heaven forbid, I had to figure out how to navigate that system and where to get the care, I would not know where to start. I wouldn't know where I would want to end up, but I absolutely would not know where to start. And I think we need to change that and not just by helping people figure out the answer, but really to change the system. It's so clear — and I keep making this comparison to mental and physical health — but if somebody is diagnosed with, heaven forbid, let's say breast cancer, it's a very clear protocol we're going to go through. [Health care professionals will say:] “This is what we're going to do first. This is what we're going to second. This is what we're going to do third. And if it doesn't work, then in six months, we're going to do A, B and C,” and we have it all laid out. And it's very clear. And certainly, mental health is in some ways more complicated. It's not necessarily such a straight path from beginning to end, as we've talked about. But certainly, we can make it so much easier and so much more efficient for people to get the care, whether it's that initial consultation with
the psychiatrist for a diagnosis, figuring out the medications, making sure that it's covered by the insurance, what are the steps of where that person should live as he or she is feeling better and gaining more independence. What do we do when that person has a relapse? How do we handle that? And so on and so forth. So, I realize that all of these are very tall orders. But those are the things that I would like to see changed.

MG: I would like to see those things, too. I think a health care navigator that would stick with a family or with a person, or both, would be something that I would love to see. I'm in a group, I write about this in my book. We call ourselves the Six Moms. And in our group, we have a physician and we have two social workers, actually, more highly trained than a case manager. One is also a psych nurse. And we're all family members who have children that have schizophrenia or schizoaffective disorder and some sort of substance abuse. So, we're the hard-case mothers, and we know a lot; of course, I know the legislative system and advocating with elected officials. We get together every three or four weeks and share how we are doing, how our sons and family members are doing. And then, we troubleshoot; we're like each other's health care navigators. And still, we're often stumped, anyway. Think of that — as educated and knowledgeable as we are, sometimes we don't know what to do next, either. So, it tells me that families starting out really need help. And we also need help all along the way because this never ends. We have first-episode programs where we do much better than when my son was first sick, where we give intensive services for those lucky enough to get in it. I've talked to families that can't get in it. We have a little of this, a little of that. Really good ideas, but not enough slots for people that need our really good programs. But the ones who get in, they get intensive help. But, I've talked to families that finish that program, because again, nothing in the mental health system is sustained. Everything is: “Here, you got this,” and then, it's over. They still end up with, often, sons and daughters who aren't working, who are lost without any friends, who are isolated, who rely on their families. We never have a sustained effort. And when we drop the ball, which we do all the time, and families wear out, even in the best of families, we have this criminal justice system that's lurking about for all of the system failures. So, we have to keep working on it. And I'm so grateful that you cover these kinds of articles in your day job on Minnesota Public Radio, Alisa.

AR: Well, I'm so glad that you've written about your experiences and that you're so willing to share your family's experiences because it's so important for us to hear from people who are on the inside. So, thank you.

MG: Thank you. Talking about it helps.

Host altro: For more information, please visit z.umn.edu/fixwhatyoucan.
This interview has been lightly edited and condensed for clarity.