Transcription

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Episode 11: "Not just surviving, but thriving': On recovery. (Mental Health Series, Part 3)

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**Sound bite:** "It's a story that needs to be told. I run into a lot of parents over the years who have just an enormous amount of frustration about how poorly the system works. You know, we talk and talk and talk about recovery, but you don't see any recovery in the mainstream system."

**Host intro:** On this podcast, Mindy Greiling, a mental health advocate and former state representative, has hosted a series of conversations around mental health care in Minnesota: the first was with Alisa Roth on the state's criminal treatment of mental illness, and the second with Dr. George Realmuto on mental health and substance abuse. In this third and final installment in the mental health series, Mindy talks about recovery with John Trepp, who she calls a "maverick" and wishes there were more like him in the mental health system. Trepp is author of <u>Lodge Magic: Real Life Adventures in Mental Health</u> <u>Recovery</u> and is former executive director of Tasks Unlimited, Minnesota's Fairweather Lodge program, which provides housing and recovery services for people with mental illness. This conversation was recorded in September 2020.

Mindy Greiling: Hello, this is Mandy Greiling, and I'm really pleased to be here today with John Trepp. John is someone I've looked to for sage advice in the mental health system for many years. He is a former executive director of Tasks Unlimited, which is a wonderful, total-package program for people with serious mental illness and like myself, he's an author of a book, and his book is called Lodge Magic. It came out several years ago, and it was a book that I read when I was looking for services for our son, Jim, who has schizoaffective disorder. And I read the book and I thought that's where Jim could do really well. And he did for quite a few years. So, John, I know you were the second executive director of Tasks Unlimited, but could you give us just a thumbnail sketch of what Tasks is all about?

**John Trepp:** Thanks for having me on here. I'm John. Tasks has grown to provide a variety of mental health programs, but the signature program at Tasks is called the Fairweather Lodge. And this was a model developed by <a href="Dr. George Fairweather">Dr. George Fairweather</a> out in California in the early '60s. It was started here in Minnesota in the very late sixties. And by the time I retired in '09, we had, I think, two dozen lodges scattered around the Twin Cities. Now, a lodge is a little hard to explain. It's a little bit like a group home, but very different than a group home. A lodge is

where a group of people live, but there's no staffing. The staff is not on-site at all. And the house is managed by the people that live there. Also, a unique thing about it compared to some other type of residential programs is it's not time limited. And it's also a program where everyone is expected to be employed. And so, typically, people are employed at least twenty hours a week, often forty hours a week, and they live there for a long time. I just happened to run into a couple of guys the other day who live in my neighborhood here, who—there's four guys in this particular lodge over here in South Minneapolis. And these four guys, a couple have been in the lodge for forty years, but the four of them, together, have been in a group for seventeen years. They've had no turnover. They're just amazing. They don't get any staffing at all. Now, they have a person who is responsible for checking in on them. But since the pandemic, six months now, that person hasn't even been in the lodge. So, they just text message them. But they've been completely on their own. And also, they pay their own way and everything, too. It's not subsidized at all.

MG: That's why your book is called *Lodge Magic*. And I can attest that magic happens in those lodges. And we'll probably get back to talking a little bit about that type of recovery before we get done here. I had a chance this spring to meet Dr. E. Fuller Torrey, who I think of as the ideal, quintessential psychiatrist. And he's written many books, including *Surviving Schizophrenia*. That's his specialty. He had a sister with schizophrenia, and I had a chance to meet him because he wrote a testimonial for my book. And I actually got invited to go to his home. And it was such a treat for me. And one of the things we discussed was the Fairweather Lodge programs that Tasks Unlimited is Minnesota's version of and he was lamenting that that there just doesn't seem to be—even though he thinks of Fairweather Lodges as the ideal place for people with serious mental illness—that they don't seem to be expanding. And I wonder if you have any insight on why that is.

JT: Well, I belong to the national organization that tries to work on that. And I don't think we have consensus about why it hasn't grown the way we would expect it to. My opinion about that is that it's because it's a grassroots kind of model. In this country, we're in love with top-down medical models where the people at the top are making the decisions about things. And the beautiful part about the Fairweather Lodge, but maybe also the problematic part in terms of marketing it is that it's a grassroots model. These guys I talk about who I ran into the other day, these four guys, they make all of their own decisions. Staff checks in on them once in a while, asks what they need, offers them advice about stuff; they can take or leave the advice; they make all their own rules. It's not a model that emphasizes how wonderful the professionals are. And I think that was Dr. Fairweather's insight back in the sixties. I happened to have an opportunity to meet Dr. Fairweather. He's passed away now but I met him in later years and he

said what he noticed when he was working in the sixties was that the staff were sincere, they tried hard and then, they went home and that was it. They didn't care until they came back to work again the next day. And what he created with the lodge is a program where your support system is the other folks in the program helping each other, and they don't go home at 4 o'clock or 5 o'clock. They're there all the time, and they're always there for each other. And they don't need staff telling them what to do and bossing them around there. It's all about that group of consumers, the peer-to-peer support model making decisions. And we've had a tremendous success with it here in Minnesota.

MR: Well, I think it's a wonderful program, and I just wish there were more opportunities. One thing I think is magical, one of many things that's magical about Tasks Unlimited is the fact that there's staff at the worksites. People when they're relaxing at home, which the lodges truly are homes. But then, the stress can come in when you're working or trying to be around more people and so forth. But Tasks has staff almost always on the worksites. And I think that's a really huge benefit.

**JT:** As you know, Mindy, that was a big emphasis at Tasks, at least when I was there, and still is, the employment piece. We strongly believe that people should be employed. In fact, one of these guys I was talking to last week retired last year at age 80. I retired a lot earlier than that. But at any rate, it's good and healthy for people to work. And I think in our mental health system, we tend to have this attitude that work is a bad idea. I've had a lot of mental health professionals over the years telling me, "Oh, we really don't want this person to work because work is stressful." Well, yeah, of course, work is stressful. Life is stressful. Living in your own apartment without a job and being poor, that's pretty stressful, too. We recognize that there's some stress involved in work, and we try to have some staff on duty. But a lot of times—I can't remember exactly what contract Jim was on—but a lot of times, we might have a crew working in a building where there's maybe 18 or 20 different folks scattered throughout the building. We might have one staff on duty in that building that they can be accessed if they need help. Well, we find most of the time is that people, once they have the job skills and once they learn how to do stuff, they don't have a lot of problems at work most of the time. And I think what happens in a normal job is they run into some problem; they don't know how to do it, and they get into a conflict with somebody and that costs them the job. I think most people with mental illness have horrible employment histories, but usually, they don't get fired. Usually, they quit; usually, they stop going to work or they walk off the job or something. And if you have just a little support there to help people get back, talk for a couple of minutes and get back to work, that usually helps a lot.

**MG:** So, you mentioned the importance of work and having a good place to live. And what do you see as some other components of the mental health system that

we, if we were going to have an ideal mental health system, even if we could think of something even better than Tasks Unlimited, but I think there's an awful lot of magical components there, what would be some of the things?

**JT:** We're so far away from that, that I don't even know where to start. And I did think about it, and I came up with four different areas in which things, at least four components of building an ideal system. The first is we have to understand the brain a lot better. We're really a hundred years behind medically, a hundred years behind our understanding of other major organs, liver transplants and heart bypass surgeries and stuff like that. We really don't know much at all about the brain. And you and I just had [surgery on] our rotator cuffs; you had yours this year, I had mine last year. Now, my shoulder works fine. Yours is recovering. Mine is pretty good. I'm playing ball again, and it's great. We don't really know how to fix the brain. And so, that's a big piece of it. Another thing I think would be to create a person-centered or consumer-centered patient center, whatever term you want to use for that kind of system; that word gets thrown around, but we don't have it at all. It would mean that they're going to be eliminating the barriers. We have all these barriers now. You get this service only for a certain length of time and then you're timed out of it, or you only get so much of it and it's not user-friendly at all. That would have to be part of the person-centered program; it would have to be much more user-friendly than it is today. Again, going back to the surgeries we had, I found when I went in for my shoulder surgery, and I imagine you did, too, the staff were quite friendly. I was happy to be there. Nobody was talking about an involuntary system there. A third thing would be integrated services. At Tasks, we try to integrate the employment and the mental health and residential, but that's not typically done. Typically, these things are all separated. Chemical dependency is another one, and then, the last one is just a recovery orientation. We really need to be able to talk about recovery. But I don't think the people running the system or typically, people working, direct service in the system, they don't believe in recovery.

MR: Well, I think that Tasks Unlimited, is, you can see people who are recovered there. And you don't see that a lot of places. And Jim, as you know, was at Tasks Unlimited for a decade. And then, for the second decade of his mental illness, he hasn't been there. So, we've experienced the other part of the mental health system. And my next question after we get off of this one is going to be about some of the other differences. But one of the big differences and a highlight at Tasks that we haven't yet talked about is friendships. And when Jim was at Tasks Unlimited for the first time, once he became ill, because once you become ill with a serious mental illness, often, you're isolated, you lose your confidence, your voices are yammering at you, so you can't focus. But at Tasks Unlimited, where people become stable due to regular taking of meds because they all take them together and monitor each other, parents don't have to do that anymore and they go to work and that's stabilizing and a good routine so important for people with

mental illness. But then, they develop these rich friendships and Jim still has friends, even though he hasn't been there for ten years that he made at Tasks Unlimited. One of them was just at our house and they were sitting on our deck last week and talked for like two hours and could have talked longer, I'm sure, because they just have this rich friendship. So, to me, that's one of the parts that the second half of our journey and mental health system, they don't pay any attention to or think it's even important. I have attended the <a href="NAMI Ramsey County Adult Mental Health Advisory Council">NAMI Ramsey County Adult Mental Health Advisory Council</a> and on behalf of NAMI Ramsey, who really advocates for a friends program of some sort, they just the staff at Ramsey County didn't even want to hear about it. They didn't think that was anything the mental health system should get involved in or spend any money on. So, do you want to comment on that, John? The topic of friends.

**JT:** I mean, anybody who's ever raised teenagers knows that peer groups are enormously important. You know, you can talk all you want about what the rules of your family are and what the rules of the school are, the rules, the norms of the community. But a person, when you're a teenager, your peer group is enormously important in shaping your behavior and how you think about things, how you see the world. I think folks with serious mental illnesses, things like schizophrenia, schizoaffective, bipolar, often develop these conditions during their teenage years. And they may not be diagnosed right away, but the conditions are coming on at that time, and it prevents them from making friends. They often don't have as good as social skills and don't have the friendships. And that's one of the things when I talk to parents, over and over again, [they say], "Oh, my son or daughter, they had friends when they were in high school, but when they got sick, all their friends abandoned them." And I don't think we can be too hard on the friends. I think the friends don't understand mental illness. They don't understand what's going on. And so, they fall away. And here's a person in their late teens or early twenties who probably isn't working. They probably aren't developing relationships. They're not making friends. I just talked to these couple guys from this lodge, [who] I ran into the other day—a couple of them were talking about their mothers. They're very worried about their mothers—both of them are elderly women in nursing homes, and they're concerned about the COVID stuff. But the one guy said, "Yeah, my family's all passed away. This is my family, these three guys I've lived with for 17 years." And these guys, they go fishing, they go to Alaska, they go do all this stuff together. There are other groups in the lodge where they take trips together. I said [to] these guys, and this wasn't a recent conversation, it was years ago, [but I said,] "It's really problematic when you guys all have to go away for a week together because we have to replace all of you at work. It's kind of a handicap, kind of a hardship for the crew at work and stuff. And they said, "But these are the guys we want to spend our time with."

**MG:** That is what helps families, too. I can say, as a mother, in the normal scheme of things—people with serious mental illness do die early for a variety of

reasons—but most parents, even with children with serious mental illness like me are going to die before their sons and daughters. And so, that is the most comforting thing of all for a parent is to have exactly what you just talked about. Of family, another family, people. Everybody else has a family that they can rely on and take trips with or just sit around and remember things with. And people with mental illness in the regular mental health system may not have that. They may have staff. Jim's opinion is anyone who's paid to be with him is not a real friend. They're just paid. And that doesn't count a bit.

**JT:** Jim is absolutely right. I knew Jim when I was working and Jim was in the program. I like Jim, but Jim's not my friend.

**MG:** Right, exactly. So, the mental health system, the rest of it, I think my strong bias, obviously, is that Ramsey County is wrong to say, "No, we don't want to have anything to do with a friends program," and they should rethink that. And all mental health systems should.

**JT:** Typically, our mental health system doesn't want to tackle employment. They don't want to tackle chemical use. They're kind of taken in kicking and screaming to deal with that. They don't want to tackle long-term planning. They don't want to tackle how you're doing with your family. They don't want to tackle friends. And that's so tragic because I'm sure it's true for you and me and most of the people listening this, your friends are your life, the relationships you have with other people. I'm retired now. And I think there's a point when you're in your thirties or forties that you're all about your job and stuff. But now, I hang out with my other old geezer friends who are all retired. Nobody talks about the work they did. They talk about their family, they talk about their relationships. They talk about their buddies and their fishing trips and card games and stuff like that. That's what counts for people. They don't care about the work. Maybe this guy was professional and made a lot of money and this guy over here was an electrician and this guy here sold suits at the mall or something. Nobody cares about that anymore. What you care about is the relationships and the friends that you've made over the years. That's what keeps you going.

MG: Right. So, yes, we definitely should do more with that. Once I got out in the world with Jim, and he got out in the world of the other type of mental health system—and I think it's affected Tasks Unlimited, too—and that is the thirty-day or ninety-day programs, chemical dependency you mentioned. And so, Jim has done a lot of thirty-day programs. It seems to be that you're supposed to be fixed with chemical substance abuse issues in thirty days and then, for mental health crises, if you manage to get in a hospital and then come to the step down program, then you have ninety days or up to ninety days in these intensive residential treatment services, places, and then, you're supposed to be fixed.

**JT:** So, one of the great things about the lodge model, and I didn't design it—Dr. Fairweather designed it—is that it's open-ended. It's not a ninety-day limit. It's not a twelve-month limit. Like I say, there's guys that are there forty years, and why should they leave? And I used to run into trouble with the county and state officials saying, "Gee, we see that this guy has been in the lodge for twenty-four years and he's never been hospitalized in all that time. Can't you move him on to more independent living?" And I say, "What do you mean, independent? He's working full time. He gets hardly any staff support at all. He's living with these other people that he likes. That's independent living. And the reason he hasn't been back in the hospital in the last twenty-four years is he has that support that he needs. Why in the world do you want to push him out?" And of course, people can leave the lodge anytime they want. The doors aren't locked. Anybody can go get their own apartment, find a different job anytime they want. Nobody's stopping them from doing that. But most of these guvs that I talk to, they're not eager to do that. They're not looking for a different place to live or a different place to work. They like what they got. Long-term stability is so good for people. The other thing I want to say about that is—I didn't start the lodge program at Tasks; it was there when I came in '78. But they didn't have the community-based training available. So, I started that first community-based training/lodge training program, and we didn't have any funding. And in that initial program, we admitted people to the training lodge, and they were there until they were ready to graduate. Over time, I connected us to the funding streams to be able to pay for everything we needed to pay for. But with the funding stream came all these strings and ropes. And now, I guess, since I left, they're down to this strict ninety-day thing. Well, some people will come in to the training lodge, and they're ready to move on to a regular lodge without any staff. And then—we [can] just back up and save our listeners—the training lodge would have more staffing, more help there, trying to help people learn how to do the stuff they need to do. And then, they go to the lodge, they get hardly any staffing at all. So, some people are ready for that in ninety days. Some people take 180 days. We had guys that took 200-plus days before they were ready to go. It makes no sense to just—we talk about this—it goes back to person-centered services. I mean, different people progress at different rates. A lot of it has to do, of course, with how ill were they when they came in. Some of them are a little more stable when they come in. Some of them are very unstable when they come.

**MG:** Yes, well, Jim must have been not the slowest, but not the fastest. He took five months to get out of the training lodge. So, if he were starting out there now and only got ninety days, he would have not survived and not been able to have those ten wonderful years at Tasks Unlimited. So, this is one thing, John, I find kind of a height of hypocrisy about our mental health system in Minnesota, and I'm sure all over the country or maybe the world. And that is that we talk about person-centered care, we talk about independence, we talk about self-sufficiency

and persons getting to decide themselves what they want to do. But then, we say, "You're done after thirty days of chemical dependency, never mind that you're still in bad shape or you have to go to a training lodge now, and sink or swim. And if you sink, too bad for you, you've been ninety days in the training lodge." We are speaking out of both sides of our mouths about person-centered care when it comes to these artificial deadlines.

**JT:** When you say speaking out of both sides of our mouth, that's what I would call a positive spin on it.

MG: Well, what would you call it, John? I love the way you put things.

**JT:** Another part of the anatomy comes to mind.

**MG:** Oh, OK. Do you have any insight about where these artificial deadlines came from? How much does money play into that? Did insurance companies dictate that our government's trying to spend money? Usually, they say follow the money if there's something really stupid going on. Is it the money, or is it some other reason?

JT: We're in love with this concept of managed care. And I'm not an expert on how managed care works in the area of physical health, but it certainly is not an effective way to approach mental health. Managed care is all about denying care. That's what managed care means. "Managed" is a nice positive kind of term. But, it's all about telling people they can't get the services. I had a colleague who left Minnesota, went to another state and worked in a clinic there. Fella came back. This is a year or so later, and we had lunch one day. And he was saying, "Oh, where I work now, we're really big on recovery." And I said, "Really? Well, that's great." He says, "Yeah, when people walk into our clinic, we give them a pamphlet on recovery. We talk about how good recovery is." And I said, "That's wonderful." He said, "And then, at twenty-four months, we tell them, congratulations, you're recovered, you're recovered. You are getting no more services. You are done. You are done getting services from your managed care provider here. I hope you do well because we aren't giving you any more services."

**MG:** Well, that's what I hate about the current mental health system because I think it's often designed for people that don't have schizophrenia or serious bipolar disorder.

**JT:** I want to say a couple more things about that. Back in the forties and fifties, people with major mental illnesses were typically in state hospitals, and they were there for a long time. I met people when I first came to Tasks who were in the lodge program who had been hospitalized only one time, and that hospitalization lasted eighteen years. And that's maybe not a great system. I'm not pushing that. But then, what happened was, we got into this idea that we've got to move people along and push them out into the community. The money was supposed to follow

them, but the money that came into the community did not end up serving that same group of people. The money that was moved from the state institutions out into these community mental health centers was much more likely to go to what I would call the "worried well." I'm not saying that people, that you and I and friends we know that have jobs and families and are not considered to be serious mentally ill, that they don't deserve services. I'm not saying that at all. But we really abandon the people with serious mental illness. And a large part of that is because we don't believe in recovery. And so, people don't want to work with that. I don't know if we've talked about this, but I knew a lot of psychiatrists when I was working who never, ever saw anyone with schizophrenia, never, ever saw anyone with schizoaffective because those people are poor. Those people are on Medicaid or something like Medicaid, and the government doesn't pay very much for that. And so, they only worked with people that had higher-paying insurance coverages.

**MG:** Exactly. And I remember one psychiatrist who had been in a different practice who came to Tasks Unlimited while Jim was there, who was just so surprised and had his eyes opened as to what people with schizophrenia could do and what they were doing at Tasks Unlimited.

JT: It was the gentleman, I think you're mentioning—I don't remember when he retired, I think he passed away—but I think when he retired, he retired before I did. And he told me—this story is going to irritate people, too (the listeners)—but he said there were two things he was going to miss in retirement. One was going to all the sporting events like the Indianapolis 500 and the Super Bowl and the World Series and stuff like that, free of charge paid for by the drug companies. And the other thing that he was going to miss was the four hours a week he spent working with the lodge folks because he said, "The rest of my practice, nobody gets better. The folks at the lodge are all getting better. They're healthier. They're going to work, they're doing stuff. They're going to Europe on vacations and buying cars and saving for retirement stuff. It's just fun to work with these guys." He was shocked by that.

**MG:** I'm sure he was.

JT: I want to jump in and add one other thing on that. We had a lot of staff over the years that have come to Tasks and love it. When I was working there, and they maybe had been in part of the mental health system somewhere else before and toward the end, I wasn't directly supervising these people because I was the CEO, and they were a couple notches down on the ladder there. But I would always try to find a chance after they'd been there for like, maybe ninety days, roughly, the staff people, and I'd pull them apart and I'd say, "Well, what surprises you? I'm not asking you what you like or don't like about the lodge. I want to know what you like about the lodge. What surprises you about the lodge model and what we're doing here?" And the one thing that they would say pretty

consistently was "I had no idea how capable these people are. I worked in this field for years. I didn't think people could do stuff. And now, I get here and you're telling me not to do it, let them do it. And I would have thought that was nuts before. And now, they can do it, I find out. I just sit here and watch them. They do most of the stuff that they need to do all by themselves."

**MG:** I would like to see people in all parts of the mental health system when they're training, coming up, being educated to spend a week at a lodge or trailing somebody who works for Tasks Unlimited just so they could know that and carry it off into other parts of the mental health system. Tasks Unlimited is a community provider. We hear so much, nowadays, about community care. We want people to get help in the community. And yet, there is the crisis times for everybody, not very often at Tasks as we just heard, but most places and sometimes even at Tasks—Jim had to go to the hospital a couple of times when he was at Tasks Unlimited—usually, connected with him using substances of some sort. And so, at those times, now, we have this big blockage of before you can get into the hospitals. And then, some people say we need more hospital beds. Some people say we should stick to community care. And my personal opinion is we need both, because if you're in huge crisis, even a place like Tasks Unlimited has to occasionally send people to the hospital, but yet, we don't have enough hospital beds. And so, what's your take on that? Do you think if we had more successful community care, we could get away with fewer hospital beds? Or will we always need some? And do you think we have enough?

JT: Well, I don't know what the number is for the last question. I don't know what that number is or percentagewise per 100,000 population. I don't know what those numbers would be. But clearly, we need a continuum. You need some mobile crisis units that are not residential. You also need the one- or two-night crisis bed kind of situation. You need the two-week community hospital, psych ward kind of thing, and you need long-term care. I mean, there are people that are going to need long-term care. And this managed-care concept that we have in our mind is not very friendly toward those things. It's all designed toward getting people out of the system.

MG: So, that's definitely what I see, too. Well, we're coming to the end. I have two more questions I want to cover. And one of them is, of course, I am a family member. So, one of them is about the role of families in the mental health system. As I said, when Jim was starting out is when he was at Tasks Unlimited. We had a couple years of disastrous, in-and-out-of-the-hospital (trying to have him be at our house) type of years. But then, when he was at Tasks Unlimited, we were spoiled as family members because we were communicated with and the staff treated us as if we were part of the team, which we thought we were, too. And it certainly worked out wonderfully. If there was any problems with Jim, all I had to do was shoot an email to his lodge coordinator and then she or he would check

into it and we could communicate on both ends and see what someone was seeing. And one or the other side would catch things early, and the other side, the family or the staff could look for it. And it just seemed to work out really well. And Jim took it as, yes, we were part of the team. He didn't at all resent us communicating. I was invited to meetings occasionally. Most of the time, I didn't need to go at all, but I at least got to see people occasionally face-to-face. And Jim and I met in a coffee shop with his lodge coordinator a couple of times when things weren't going as well, and we all talked about it and troubleshot and Jim just took that as that was a normal part of life for him and for us, and that would all work together. When he got in the other half of the middle of his time in the mental health system, we found that it was night and day. We found that unless we asked to be involved, we typically weren't. Or maybe there would be, the really good places like he was at Andrew Residence; it was really good with families. We met with them quarterly to see how he was doing, but it wasn't a day-to-day working. But they were very available. But most places where he was like with ACT Teams [Assertive Community Treatment Teams] or just dealing with having a case manager wherever he might be, they were very standoffish or even not friendly about us being involved. We would get answers if we absolutely asked. but otherwise, we were kind of supposed to stay back. And I think that didn't work out very well for Jim, as anyone can see if they read my book. And so, why did Tasks do it so well? And why do you think the rest of the mental health system does that so poorly?

**JT:** Well, I'm glad to hear your perception that it went well. I didn't feel we were very good at that. And if I was going to start over and do another thirty years at Tasks Unlimited, that would be a major thing I'd try to do a better job of. One of the things that I think that's part of what's going on there is that a lot of the people coming into the program are, let's say, maybe in their twenties and a lot of the direct service staff that are starting out in these direct service positions are in their twenties, and the parents are usually in their fifties. The staff, quite frankly, are scared to death of the parents, and they consider the parents to be problems. And I would talk to staff about, "We've got this garden planting coming up here next week and we want you to try to get the families over to maybe work together and plant a garden or something along," and they say, "Oh, I don't want to do that. I don't like my parents much. I certainly, heck, don't want to talk to my lodge members' parents and stuff like that. They're sort of afraid of them. That's part of it. They haven't been trained for that, and I don't think that that's unique to Tasks Unlimited. I don't think they get trained for that anywhere. I think as I grew, as I matured, by the time I retired in my sixties, then, I was a little more sympathetic to the plight of parents trying to figure out what to do about that. Everybody wants to see their kids do well. And it's very frustrating. And I don't need to tell you this. I've read your book, and I've heard the story even before I read your book, but it's so frustrating when you've got this bright child; you've got high expectations for them. And the last thing you're thinking of when they're

growing up is they're going to develop this terrible mental illness that's going to derail their life. And when it happens, it's very frustrating for parents. And it makes it hard for the parents to talk to the staff and hard for the staff to talk to the parents. Looking back, I can see very clearly that the family members—not just parents, because sometimes it's brothers and sisters, sometimes it's even kids (sometimes, the people in the lodge program have kids that are involved)—they have to be part of the treatment team, really. You don't have to call it treatment team, but they have to be part of the solution to having this person get healthy and to be recovered and stuff like that.

MG: Well, I'm sympathetic to the young staff, like you mentioned, because I was an elementary teacher. And so, there wasn't that big age gap between the parents and me when I was teaching, because I started out when I was twenty-two and some of them were only a couple of years older than me at times. But even so, I think as a new teacher—and I only managed to teach for five years and went on to other things—but I think parents are intimidating. Because they're judgers, they want to know that things are good for their kids and they want to know what are you doing about that. And so, I think the mental health system is similar. And you just said that it is. And so, I'm sympathetic with that. But on the other hand, especially if Jim isn't doing well, I think a lot of parents become very active and have to learn to be assertive advocates. I didn't have to do that at Tasks, but I've had to do it more than I care to think about in the second part of our time in the mental health system.

**JT:** I remember when our kids were growing up, we sometimes didn't feel that the communications from the teachers at school or the coaches on their team was as good as it could be. And I know now I've got grandkids and and my kids are complaining about their communication. So, it's always difficult. People don't get training in this. And I think the one thing, if I did anything right on this topic, this domain at Tasks, at least I would preach to our staff that we needed to talk to parents and we needed to involve parents. We didn't always do it as well as I'd like to, but I was always on their case about trying to do it.

MG: You set the model and then also, Tasks had—I think you did it maybe twice a year—you had potlucks, which were for families and for lodges, and everybody brought food. There were mountains of food. It all got eaten, as I recall. So, families got to see that people in the lodge are pretty darn good cooks, too, and bring their favorite things. And there was no way to tell who brought what food. And it was all delicious, but also then, families got to meet other families. Staff in a more-relaxed atmosphere could joke around with families and not have to just be talking to one set of concerned parents or something. And lodge members could see that the staff and their families were friendly and that just facilitated and oiled the whole thing. And then also, at Tasks, there were family meetings, I think maybe, they were once a month; but something on that order that were

optional for families. But I often went and then, I got to meet other families. There might be a topic where the Tasks person coordinating the meeting could share things. I remember one time, the coordinator talked about where could you buy clothes? Because often, people with serious mental illness taking these heavy-duty drugs gain a lot of weight due to the interactions going on in their body that make them feel artificially hungry. And that happened to Jim. And so, one topic just was where to buy clothes because you needed bigger clothes sometimes than what you could find at the mall. I had a chapter on that in my book. And so, those were things that made parents feel included. And once you had actually met the staff and communicated with them, then, if there was something going on, you were more apt to approach them. And I think that's missing in the mental health system, in general.

**JT:** I just want to go back to this question about friends and friendship and relationships. Our top-down mental health system is just hypervigilant about preventing any kind of relationships between staff and the people being served because, oh, my God, somebody might end up sleeping with somebody. And obviously, that's not something you want to have happen. I don't think it ever happened at Tasks when I was there. But because of that, this hypervigilance, there's all these barriers. If you go to these professional things, they're always talking about boundaries and stuff, like the be-all about how you should do stuff. I didn't have that opinion, and I didn't preach boundaries. And you're talking about having these picnics and stuff and getting together. And I would bring my kids to these things, and and we would play. If we had a picnic, we ended up playing softball or volleyball, and I'm on a court—and I'm playing with, I don't know these people are half the time—and it's just about being a normal kind of a healthy environment for people. I had a friend who was a mental health therapist and a person she had been working with died in a tragic incident. And she wrote a story about that. And it was published in a local paper. And she was nervous about referring to that person as her therapy client because there was kind of a confidentiality thing and she didn't want to use that term. And so she referred to this person who had died as her friend. She had been the therapist for this person for many, many years. The woman got censored by the Minnesota Board of Social Work because you're not supposed to be friends with the people you're working with.

**MG:** Oh, my gosh.

**JT:** I was always pushing back on that. Sometimes, I get myself in trouble talking about that. I obviously didn't want staff to be sleeping with clients, but I wanted people to be friends. And these guys I run into now in the neighborhood, I'd run into them before COVID, run into them in restaurants and run into them at a Twins game and stuff, these are my friends. These are people that we worked

together with. It wasn't like I was the boss, and they were the patient. We were in this together.

**MG:** I think it's poetically balanced that both you and I, now that we are retired, are active in our respective NAMIs. You're active in NAMI Hennepin and I'm active in NAMI Ramsey. And that just shows that we are continuing to be involved. And what you do in your volunteer life is part of friendships as well. And it's all a beautiful package. And you mentioned normal relationships.

**JT:** Let me just jump in and say I'm not friends with any of the staff.

MG: Well, that speaks volumes. There you go.

**JT:** I'm retired 11 years. I don't do anything socially with the staff.

**MG:** Well, you love the clients.

JT: Yeah.

**MG:** So, normal things, that living a normal life is what everybody wants. And so, you mentioned that some people in the mental health system don't think recovery is possible. And you've given us a good idea of the fact that clients, even with serious mental illnesses like schizophrenia, do recover, do live normal lives, do take trips and so forth. Do you have anything to add about what recovery really means? And if you had to list three ingredients for recovery for somebody with serious mental illness, what would those things be?

JT: Well, you're not going to limit me to three, are you?

MG: You can say more. I'll let you go farther.

JT: I've got a couple of things to say. One is that these guys that I ran into here a couple weeks ago—even among lodges, they're kind of like superstars. I mean, not all lodges are going to work as well as this. But these four guys have been living together in this house with basically no supervision at all for seventeen years. None of them have been hospitalized during that time. None of them have been arrested, as far as I know. They're all working. One of the guys retired now last year at 80. Two of the guys own a boat and a motor together, they go fishing all the time. These guys go on trips. These guys are recovered. This is what recovery looks like. We talk and talk and talk about recovery. But you don't see any recovery in the mainstream system. This is what recovery looks like. This is maybe going to be a reacher off to another topic. As I was thinking about this the other day, I remember this advertisement I saw years ago and it was a print ad for the University of Minnesota. And it was a very simple, very powerful ad. It was just a photo of this guy, this kid that looked like he was ten, twelve years old, I don't know. And he was playing Little League and he was sliding into home plate.

And there was another ten-, twelve-year-old kid trying to tag him out. There's an umpire calling him safe and there were parents cheering in the background. And the only words on the ad was that this kid, Tommy, I can't remember what his name was, had had a heart transplant at the U of M two years earlier. And I get choked up when I think about that now. I get choked up about that ad. That's a powerful ad. They weren't telling you a bunch of statistics about how many heart transplants they did and how wonderful they are. They were showing you this kid sliding into home plate, and maybe he's safe. Maybe he's out. Who in the hell knows? The important thing is he's recovered. He's out there playing Little League for crying out loud. And that's what I want for people with mental illnesses. I want recovery. I don't want them to be surviving in the community. I want them thriving in the community. I want them going on fishing trips to Alaska. I want them buying boats. I want them having friends and buying cars and going to the Grand Canyon. That's what I want them to do.

**MG:** That is beautiful and that's recovery. "Thriving," I really like that word. One thing I just wanted to say, we've been talking about the guys at Tasks Unlimited because it is a lot of the clients are men, but there's plenty of women there, too. So, if anyone is listening and has a daughter with serious mental illness, just know that Tasks Unlimited is for men and women.

**JT:** Yes, it is. They serve more men than women, but yes, absolutely it works. And statistically, the women do just as well, if not better than the men. But we get more men referred into the program.

**MG:** So, John, thank you so much for talking with me. You're just one of my favorite people because I love how you bend the boundaries and push the walls of the mental health system and that you're continuing to do that. And I try to model you everywhere I go. Thank you.

**JT:** Let me just thank you for your book. I had a chance to read the early copy that came out. And I just think it's a great story. It's a story that needs to be told. I run into a lot of parents over the years who have just an enormous amount of frustration about how poorly the system works. And I share your frustration.

**MG:** Thank you, John. And I thank you for your book. I think people should know that it's there, *Lodge Magic*. You can look it up anywhere on a bookstore or Amazon. Whether anyone's interested in sending someone to Tasks Unlimited or not, it does include vivid pictures of recovery like you described, and happiness and thriving. So, that's what everybody wants for their family members or their friends. So, if you're in another part of the mental health system, you could still learn from your book as well about how to make that part better. Thank you.

JT: Thank you.

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