NAMI Ask the Expert
People, Place & Purpose:
A Vision for the Mailing Mental Health System
Featuring Dr. Tom Insel

Dan Gillison (00:00:00):

Welcome to our session, People Place and Purpose: A Vision for the Failing Mental Health System, featuring **Dr. Tom Insel**. We're so happy to have Tom with us on today, Dr. Insel. Let's go to the next slide, Jordan, and we'll get right into the introduction by Dr. Duckworth. Now, just something that we want to say to you right here is the following. If you need support while hearing our story today or at any time, remember that you're not alone. That's the most important thing we want you to know. And then consider reaching out to the NAMI help line 1-800-950-6264 or info@nami.org. And also visit us at nami.org/help. So remember you are not alone. We're so glad to have you with us here today. And whether you're on the West Coast where it's early for some, those in the East where it's afternoon, good afternoon, and good midday to you. And now I hand it off to our chief medical officer, Dr. Ken Duckworth. Ken.

Dr. Ken Duckworth (00:01:04):

Thank you, Dan. And thank you, Jordan. We're very fortunate to have **Dr. Tom Insel** today. I'm going to briefly introduce him, which we'll do no justice to his remarkable Renaissance career. Tom Insel was the National Institute Of Mental Health director for 13 years. Did interesting research things at Yerkes Primate Research prior to that then went on to become a leader in technology. So he went to work for what was then called Google in mental health. And then he co-founded two companies that do mental health support for people. So we could talk about technology and the role of online support. We could talk about so many things. Dr. Insel is a friend of NAMI attended every NAMI convention for many years, gave great and well attended talks. Tom is a member of the National Academy of Medicine. And I don't know if you know how hard that is to get into. So I just want to say, Tom, we're very fortunate to have you today and we look forward to learning from you. Please send in your questions as you hear them. Tom wants to have a robust discussion with our community. I'll do my best to sort them, organize and have a conversation with Tom based on your input. Thank you and welcome. Tom.

Dr. Tom Insel (00:02:32):

Thanks Ken. Thanks, Dan. And thanks, Jordan. I am so excited to be here. I feel like NAMI is kind of my second home. You're my peeps. So this is just a great chance to have this conversation. I do want to show a few slides, but let me start with a story, which is that as Ken just mentioned, I spent a long time in government, in Washington and I have a lot of affection and admiration for the National Institutes of Health. And being director of NIH was certainly the pinnacle of my lifetime in terms of career.

Dr. Tom Insel (00:03:15):

I got to this moment where I began to wonder with all the progress we were having in the science of mental health, why we weren't seeing more progress in the outcomes for people with mental illness. And some of you've heard this before, but I often tell the story that I was talking to a group on the West Coast of mostly family members, a lot of NAMI members, and showing all the spectacular research we were doing, beautiful images of pathways in the brain.

And somebody got up afterwards and said, "You don't get it. Our house is on fire and you're taught about the chemistry, the paint. I've got a son with schizophrenia. He's been hospitalized five times, been incarcerated three times, two suicide attempts, and he's currently homeless. What you're telling us, that's not helpful."

And that really got me thinking about how difficult it has been to make this transition. And it was that kind of concern that our science hadn't really served those who need it the most. That got me started on this journey. I left the NIH, spent, as Ken mentioned, some time in Silicon Valley, worked at a bunch of different tech companies, some of which I joined, some of which I started, some of which I've invested in, thinking that technology can make a big difference. And I still think it can, but there's a lot more that we need to do.

All of this led me to write this book, which is called Healing: Our Path from Mental Illness to Mental Health. When I was working on the book, I did a lot of research and I spent a couple of years traveling around the country, actually around the world, trying to get ideas about not so much about the problems, but about solutions because I really wanted to focus on what was working and to provide a more hopeful picture for people.

I put together because I came from this academic background, a ton of data, lots of great images. They were in the manuscript and my editor said, "What are you thinking? Nobody wants to see all these images. So the first thing you have to do is get rid of all that." So that's where I want to start with you because I want to show you what I was able to learn in the course of two or three, actually more like five years of trying to understand this problem. And the problem I was trying to understand was that conundrum of why we've done so well in science, why we have really good treatments for the most part, why more people are getting more care and yet the outcomes are worse?

How do you square that? How does that make sense? So it was on that basis that I got started on trying to first say like, "Where are we?" I'll define the problem in terms of morbidity and mortality, or if you want disability and death. And when you do that, what you see here is that the disorders that we care about here, brain disorders, neuropsychiatric disorders have really become the largest source of disability, of all medical causes.

These are data from the Institute for health metrics in evaluation in Seattle that may measure... They have a way of measuring disability. And it's not going to surprise you because if you think about what we're up against, the increases and prevalence of unemployment, homelessness increase in incarceration. The fact that people with serious mental illness die somewhere between 15 and 23 years early, then just the effect this has on incoming equality and poverty.

Dr. Tom Insel (00:07:20):

All the numbers are going in the wrong direction. And it's true as well for mortality. We've made enormous progress in so many areas of medicine, but when you look at suicide as an outcome, the numbers are going unfortunately in the wrong way. About a 35% increase since the turn of the century. And if you begin to think about not just suicide, but drug overdoses, alcohol related deaths, the so-called deaths of despair. You can see how those numbers not only have they climbed since 2000, but they're continuing to climb considerably during the pandemic.

This is not the story that we want to be able to tell. And we have this kind of odd mismatch between the experience that Ken or myself or others would have where individual patients seem to be doing better than ever before, and yet population wide, we just aren't making the impact.

Why is this? Well, first of all, I'd say, unlike the COVID crisis, this is a care crisis. And in some ways, those are easier to solve. When I walked around asking people, "Why do you think this is happening?" these are the answers I usually got. I want to refute each of them. I think that to say that we don't know enough is really just an excuse. The fact is we never know enough and we never will, but that shouldn't keep us from being able to solve the problem of incarceration or homelessness.

Is it true, we don't have enough therapists. Well, we have about 700,000 people in the mental health workforce according to SAMSA. There are 200,000 people in the primary care workforce. 200,000 people in the dental workforce, 700,000 a lot of people. And yet, somehow people say they can't find a therapist. Interesting problem. We don't have effective treatments. I heard that a lot. I don't know where people get that idea, but my argument would be that if you look at the treatments we have medical, psychological, kind of neurotech, neuromodulatory treatments, and most of rehabilitative interventions.

They stack up really well with anything else in medicine. Are they cures? No. Are they magic bullets? Absolutely not. But these are effective treatments. And we can't forget that. And in fact, it's knowing that, that makes this problem particularly tragic. A lot of people will say we don't spend enough. And as an advocate, I've spent a lot of my time trying to get people to spend more money on this problem.

But the reality is it's gone up 52% since about 2013. We're at about $240 billion or something like that for the mental health spend. If you add in all the indirect costs, that's easily a trillion dollars. It's not like we're not spending money. The problem is we're spending money in the wrong way and that's a very different, but also in some ways, convenient problem to have.

Everyone I talk to at some point brings up stigma. And I have to tell you, I do not like that word. I think it's a word that perpetuates a sense of victimhood. Not helpful for promoting change. So I would actually want us to change that word to the extent we can to the word discrimination, which is actually a more accurate description of what we're up against and I think is more likely to generate activity rather than just the sort of passive response that we've seen so far.

Dr. Tom Insel (00:11:07):

So if those aren't the answers, why do we have this crisis? And since I come from the tech sector, I got to say in tech, we spend a huge amount of time getting very, very careful about our problem statements. We've worked really hard to say, "What is the problem we're trying to solve?" And we really try to narrow that down. And then we pick a very particular pathway to try to solve it. So I'm going to take that kind of an approach here. It's not going to be one thing. But there are a bunch of things that contribute and I want to run through them very quickly.

Problem with capacity, problem with engagement, problem with quality, problem with accountability, and we'll talk a little bit about each of these, and a problem with equity. And these are each things that we need to sort of focus on. I'm going to take just a moment if you will to just unpack each of them. So the capacity thing, very important for us to understand this. We've talked a lot at NAMI about deinstitutionalization.

Actually, the problem is transinstitutionalization. This figure, actually, I did get into the book, but almost everything else had to drop. But I felt so strongly about this because it shows why in some ways we're in this absolutely egregious situation of criminalizing people who have serious mental illness. There just isn't an alternative in terms of people who need a bed, people who need to be institutionalized.

95% reduction in state hospital beds and beds in the public mental health system. There's been an increase in the private system, but in terms of public beds because of IMD and lots of other things, those are largely extinct.

So what we're left with is the defacto mental health system in the criminal justice world of jails and prisons. And you can see that number now has exceeded 2 million jail cells and prison cells. And that is often where people end up, as all of you know. There's about a 10 to one ratio of people with serious mental illness being incarcerated versus being in the public health system.

I mentioned lack of engagement. What do I mean by that? Well, we've got about 14 million people with serious mental illness. The odd thing is when look and you see that only about 40% of them are receiving services. According to NIMH about 40% of those receive what would be considered scientifically based or minimally acceptable care. And at that level, when they get that kind of care, about a third get well, a third get some benefit, a third don't really improve.

I call this the 40-40-33 rule. I talk about this a bit in the book, because I think it's really important to understand that one reason many of us have the sense that we're doing better with the people we see, than we've ever done before, that's great. But the people we see are a tiny, tiny fraction of the people who could and should be in care. Massive problem here. Not a problem that you see so much in oncology or cardiology or any other part of medicine. But the inconvenient truth in mental health care is that most of the people who need the care are not in it, and some of those people who need it the most or the likely to get it.

Dr. Tom Insel (00:14:38):

That's a real challenge for us. They're going to have to solve that if we want to be able to change outcomes at a population level. Those people who do get into care as all of you know, what they find, "Oh, it's not great. It's not just that it's delayed, but it's so fragmented. It's so hard to navigate. The care you get depends so much on who you go to see, and no matter who that is, it's probably the case that they're not using any kind of measurement-based care.

So massive problems here. I put it a few of the quotes that I kept hearing over and over again, some people have said this system is truly broken. Some people have said, "It's not a healthcare system. It's a sick care system. It's all about crisis. It's all about incentivizing people to get care when they're in crisis, but not before and not even after."

So not surprising that what we have is what we're paying for. A lot of people said, "Particularly, here in California, this isn't even a system. It's just incoherent. It's chaotic, and it's very, very difficult to navigate."

When I wrote the book, I was really writing it for families because I kept hearing this idea from families that it's not just that they are often the caretakers, but they're the first responders. They're the care navigators in a way that a kid doesn't really... You don't find that in many other areas of medicine and you yet oddly enough, they're kept out of the care system. They're not included in the meetings. They're not part of the planning. No one would ever think to reimburse them, even though families are fundamental to what we'll talk about the moment which is the recovery process.

I just want to skip to this last piece about equity because obviously as a nation, we're in the middle of a long overdue reckoning about race and that we need to have that conversation. It's incredibly important and it's one that I think as a country we still haven't quite figured our way through. It's important to know that people with serious mental illness on many of the same outcomes that we worry about in terms of racial inequality like life expectancy, unemployment, use of force by police, and on risk of incarceration that irrespective of racial or ethnic or geographic background, people with serious mental illness, if they were a subgroup would be the worst off. And of course, people with serious mental illness when they're people of color as well are even... That's double jeopardy.

They're far, far worse off. But I think it's important for us, and by us, I mean the mental health community broadly to understand this because this has happened on our watch. This is us. This is our problem. That those people with serious mental illness in many ways look the untouchables in our society. They are truly the most disenfranchised part of our population. Whether they're incarcerated or homeless or unemployed, they're dying early. They're really worse off in terms of these measures of equity and we haven't had that reckoning yet.

Dr. Tom Insel (00:18:09):

I don't ever hear people talking about this. It's kind of unremarkable to me because people are perfectly willing to talk about unemployment. They're willing to talk about incarceration and homelessness, but they don't seem to recognize that so much of each of those problems lies within this world of untreated serious mental illness. And I think it's going to be important for us to have that reckoning sooner rather than later, especially if we want to begin to solve the problems of unemployment, incarceration, homelessness, all of those things.

As I mentioned, part of what makes all of this particularly tragic is we have stuff that works and it's so important for the public to understand this. It's not simply writing another set of medication prescriptions, but medications are part of this. But the psychological care, new neuromodulatory treatments, these rehabilitative interventions, together this provides a very powerful set of interventions.

We're not using them. The rehabilitative interventions are paid for often by Medicaid. The psychological treatments, the ones that work are often not provided by much of that workforce of 700,000 people. So we've got to take ownership of this. We've got to admit that we need to do better. But we shouldn't lose sight of the fact that the solutions, the interventions are right there. They're hiding in plain sight. And it makes all of this both at the same time tragic because we haven't used them, but also incredibly hopeful to me because we know what to do.

Now, what I've been talking about up until now is how to fix the mental healthcare system. And it took me a long time in writing the book. And it was really kind of the last third of the book that's about this when I began to realize that if the real issue here is this engagement problem that so much of what we're struggling with is outside of the healthcare system, then we've got to rethink this a little bit and we've got to figure out a way to reframe what we mean by care.

I came at this because of my background with a very kind of rigid medical model. These are brain disorders and we need to hit them through healthcare. I was in Los Angeles talking to a psychiatrist who works on skid row there. And he was really challenging me on all of this saying, "You really need to start thinking about recovery as a different kind of model."

It's not either or, it's both/and we need the medical model. But the recovery model is super important. And when I said to him, "What do you mean by that?" He said, "Well, it's simply the 3Ps," and it's the title of this presentation: People, place, and purpose. We're not talking about that, we're not providing that. We're not reimbursing for that and yet we have to understand that if we care about mental health, it's not just mental healthcare. It's not just more prescriptions, more clinic visits, more hospital beds.

Yeah. We need all that. That's super important, but it's not going to get us to where we need to be. I mean, just in the most great sense, if 65% of people who die by suicide are not in the care system, we're not going to change the suicide numbers as much as we want, if we're just fixing the care system. We have to be able to enlarge that system. We have to think about this engagement problem. We have to think out how do we meet people where they are?

Dr. Tom Insel (00:22:11):

We have to think about setting up a new set of goals. So I end up, and this will be the last comment, thinking that it is important to define the problem as medical, meaning that these are brain disorders and they should receive the same rigor and the same reimbursement and same kind of science, and the same serious engagement as any other medical disorders. They are just as disabling, just as lethal.

So the problem is medical, but the solutions need to be defined as social, environmental, and political. So what I'm saying is you have the medical model works in some sense, but not enough. We're going to have to bring in this other model, this recovery model, thinking beyond symptoms and actually increasingly redefining care so that we provide something far more than just the reduction of symptoms, but we give people, place, and purpose. So let me still up there. Ken, I see your back.

Dr. Ken Duckworth (00:23:12):

I'm back. Thanks-

Dr. Tom Insel (00:23:14):

I took more time than I wanted, but I'd love to-

Dr. Ken Duckworth (00:23:17):

Great.

Dr. Tom Insel (00:23:17):

... with that as a preamble, begin a conversation.

Dr. Ken Duckworth (00:23:20):

So I want to encourage everybody to send in your questions to Dr. Insel. First question I have is you traveled America looked at all different kinds of program. Did you have one that stuck out to you as something that we should be implementing across the country?

Dr. Tom Insel (00:23:39):

Yeah, many. I have got lots of great stories. Actually, when I started the tour, I thought this is going to be really depressing. It was actually just the opposite. It was inspiring. I was really blown away by what people were doing often with very limited resources, but doing and doing well with having a huge impact. I liked the clubhouse model. So I loved spending time at Fountain House where I now serve on the board in New York. That's one.

But there are 300 clubhouse across the country. Some are great. Some are not so great. I went to one that I write about in the book in this remote part of Southern California in the high desert country, which I just found absolutely inspiring. It was so great to see that. I've been impressed by seeing how people have developed new methods of crisis response.

Dr. Tom Insel (00:24:40):

Now, what I was just saying is we've got to think beyond the crisis, but I think we're at a moment where people are very focused on 988 and changing the way we respond to crisis. I spend some time in Phoenix and Tucson where they've created just an incredibly wonderful continuum so that if you do have a crisis, there's someone to connect with right away? You get a mobile van, not cops with guns. If you do need to be someplace safe, they take you to a drop off center, not a jail, not a psychiatric... Or not a medical surgical ER.

There are people who are fixing all of the big issues all over the country, all over the world. I mean, there's a lot of innovation, a lot of really promising stuff. It just hasn't scaled. I think good things are happening everywhere, but they're not happening. Things that we need aren't happening in as many places as I'd like.

Dr. Ken Duckworth (00:25:45):

Yeah. If those of you are interested, Margie Balfour runs that program in Tucson, Arizona. She was probably on an ask the expert a year ago. So if you were interested in more detail about Arizona and Georgia, which are two of the leading states on providing crisis response, that webinar is available. Tom, let's talk about 988 while on crisis. This was NAMI's great recent advocacy achievements, done with the coalition of other players, but our policy team worked very hard on it. Do you see 988 as a material upgrade on July 16th when it comes out? And what else needs to be done? Because it doesn't really create mobile crisis services, it simplifies the steps.

Dr. Tom Insel (00:26:32):

Yeah. So we need to talk about this. I mean, I think we have to manage expectations. It's important to know that 9 11 took a long time to get working well. So when July 16th rolls around, in what, eight weeks, 10 weeks? It's a marker. It means that we'll have a new number. I'd like that to serve as a kind of catalyst for lots of other things to happen. Important to think about 988 as kind of the beginning of us transforming crisis care and what we need there is not just a new number, we need old continuum.

SAMHSA likes to say it's someone to call, someone to come some place to go. And that's a really good formulation I think. We need all the three of those. That's what has been built out in Tucson, Phoenix, and Austin, Denver, Atlanta, a few other places. And each part of that, there's a lot to unpack. I'll just say that the simple thing I think we should remember and I've written quite a bit about this is that 988 is not 911 for mental health. 911 is a dispatch service.

988 done appropriately can handle about over 90% of the calls that come in. With a 911 call, the dispatcher is on for 30 seconds, maybe two minutes, sometimes 10 minutes. 988, done right, the person who answers the phone is doing telehealth. They can be with you for an hour or more and they may call you back the next day if it's done right. And if it's done really well, they're going to call you back a week later.

Dr. Tom Insel (00:28:18):

So it's a really different formulation of what this could be if we think about it in the right way. It could be in the beginning of the providing a national telehealth service. How cool is that? And then if it links to mobile crisis and it links to psych ERs and crisis stabilization, we can begin to solve this issue of incarceration, bad interactions with criminal justice, crowding of emergency rooms. All of that is fixable and could be within the next five years. We just have to understand that it's not just a new phone number, it's a whole continuum that needs to be built out.

Dr. Ken Duckworth (00:28:56):

Yeah. Thank you, Tom. There'll be an as the expert on 988 coming up for those of you who are interested in its potential to improve things. Tom, you've covered the whole waterfront in your book, which I read very happily. Let's talk about lack of awareness of illness. The medical term is anosognosia. What is the best role for intervention? Do you have a take on that? Obviously, a painful area for a lot of family. And it's come up in a couple of questions from the more than 650 people.

Dr. Tom Insel (00:29:31):

Yeah. So I devote a chapter to that because it's a tough area. There's no simple solution. There are solutions people have talked about like advanced directives and how useful that can be. I think we need to change this conversation a little bit. The way the conversation always goes is around civil liberties, involuntary treatment, that whole range of issues which ever seem to get resolved. And by the way, I don't think it's been helpful. We're in the middle of this, by the way in California.

We have this new bill, which by the way, got voted out of committee yesterday afternoon called the care court, which mandates treatment. It actually mandates treatment in two senses. It mandates that people who are homeless and have a diagnosis of schizophrenia must accept housing and must accept treatment. What's super interesting is it's a two-sided mandate. It mandates that the county must provide a whole range of services, which often has not happened.

And I think we're going to get more resistance from the counties than we are from the civil liberties lobby. That said, Ken, I think the key is, and where I would really love to take this conversation nationally, as we start to get at this is to help people to understand the nature of these illnesses.

I think that those people who are so opposed to involuntary treatment... They're imposed involuntary treatment for a 22-year-old with schizophrenia, but not a 72 year old with dementia. They get that. The 72 year old needs to be put into care. But the 22 year old, I think they don't understand the nature of the illness. I don't think they understand that when you're talking to somebody who says, "I want to be homeless, the voices are telling me to do this." You're talking to their illness. That's not the person. There's a person inside there who's actually some part of them that still wants to get well. They know that what's going on is a struggle. It's like demonic possession.

Dr. Tom Insel (00:31:48):

It's very easy for us, and maybe in fact the lowest resistance thing is to side with the illness and not with the person. I think we confuse identity and illness all the time here. We start to think that this person is not just that they have an illness called schizophrenia, that they're schizophrenic. This is who they are. It's not who they are. It's an illness they have. It's like having a broken leg. You need to treat that and you need to liberate the person behind it so they can begin to have a life again.

And unfortunately, they can't do that themselves. Some of them can, and soon they get well enough to begin to fight, but a lot of people are going to need someone else to help them. And we're not doing that. We're not helping them. So I think that's the kind of conversation to begin to have. It's so interesting. And the way to have it, and we haven't done this well, particularly here in California, we have really not done this well, we need to bring in people who have recovered to talk about this.

The person who says, "Why the hell did you leave me on the street for two years? What were you thinking? In what world is that okay? How is that moral?" You have to hear people tell you that story and then you get it. But I don't think the public has heard that story.

Dr. Ken Duckworth (00:33:10):

Well, Tom, you are a polymath and so we're going to cover multiple areas. One of the great achievements that I think about your run at the National Institute of Mental Health was the application of ketamine for treatment resistant depression. So there's a couple questions about ketamine, your take on it, how you get it, access to ketamine. And then of course the related question would be the stereoisomer putting ketamine in a mirror. And the idea that is a treatment that is FDA approved. But some people have found hard to get paid for by health insurance companies.

So this is the topic. This is a company softball pitch for you, Tom, because you were one of the leaders to help create ketamine as a new construct. So I want to make sure we touch upon this.

Dr. Tom Insel (00:33:58):

Yeah. It's a little complicated, but the short story is the data are pretty good that ketamine given intravenously to people with treatment refractory, major depressive disorder do pretty well. Now two things about it. There's a very rapid response. So that's incredibly important because we had all gotten into this mindset of thinking that giving someone a medication for six weeks and then beginning to see an improvement was good enough. Ketamine shows us that we should be in a mindset of saying what can make somebody better in six hours because that's how it works.

The problem is it doesn't last right? So most people relapse sometimes within a week, sometimes mostly within a month. And so they need another infusion at that point. But the data I think are pretty compelling that this works pretty well. It also reduces suicidal ideation, which is super interesting and may have a role eventually in the emergency room for people who are acutely suicidal.

Dr. Tom Insel (00:35:08):

But as you say it has been approved by the FDA, Spravato. It's a product that was developed by Jansen. Part of Johnson and Johnson. It's not the full ketamine. It's one chemical variant of ketamine that's available as a nasal spray. It's probably equivalent, generally, I think that the response, the data with Spravato in their clinical trials looks about the same as the infusions. But what's happened is even though it's approved by the FDA, a lot of insurance companies don't want to cover it. It's expensive.

And what's ended up happening is we have now I think 153 clinics across the country often run by anesthesiologists or nurse practitioners where people go to get... They may get Spravato, but more often, far more often they get intravenous ketamine what all the NIMH research was done on. And they come back every month. They get another infusion and they plop down a thousand dollars per treatment because insurance doesn't cover it.

It's an unfortunate situation because it means that it's in this fee for service model. It's a cash pay. So much of mental health care is that way. And we are going to need to figure out how to get insurance coverage for something that scientifically appears to work, and that's in some version approved by the FDA.

Dr. Ken Duckworth (00:36:45):

Yeah. Thank you. Tom, we're going to keep covering the whole waterfront. Three people ask the question in different ways. "I'm not a clinician, I'm a citizen, regular person. What should I be doing, saying, or engaging in to improve the conversation around mental health and mental illness?"

Dr. Tom Insel (00:37:06):

Well, I think one thing you should do is you should read this book that's coming out by Dr. Duckworth which it gives a pretty good sense of what recovery can look like and what we should be aiming for. I can't remember the name of that book. Do you remember the name?

Dr. Ken Duckworth (00:37:22):

You Are Not Alone.

Dr. Tom Insel (00:37:23):

You Are Not Alone. Right. I would read that. I would read my book which is already out. Just as a way of getting educated and essentially getting hope as I think a critical piece of this as a citizen is to understand this is a solvable problem. It is a solvable problem. We have everything we need to solve this. And if you have any doubts about that, and I often tell people this and it's hard to grasp, but we did a lot better for people with serious mental illness when I started my career than we're doing now.

Dr. Tom Insel (00:38:09):

We didn't have nearly as many medications. We didn't have all these fancy psychological treatments. We didn't have anything for neuromodulation, but we had better care. And that tells you that we could do a lot better than we're doing now simply by providing better care. So what can you do? You can advocate for that. You can help everyone to understand that there's hope, that people can recover. People should recover in this world, in this society.

I think there's an opportunity to try to change some of the policies. As where NAMI can be really helpful is to advocate for some legislation. And it's not just spending more money on this problem, but making sure that we're paying for the things that matter. I think it's just ridiculous that we've got a healthcare system that today eats up about $4 trillion, almost 20% of our GDP and yet it doesn't pay for a clubhouse. What's with that?

It doesn't pay for ACT teams. It doesn't pay for stuff that we know are really effective. It maybe true that it doesn't pay for ketamine. But first let's get it to pay for stuff that we've known for 30 or 40 years helps people recover.

Dr. Ken Duckworth (00:39:33):

Supported housing, supported employment, the things that help people with functionality. Thanks for the plug in the NAMI book. All proceeds go to NAMI. What I did in the book is I interviewed 130 people with real lived experience who were using their names to share what they learned. The idea is real people, not composite people, real people using their names, sharing what they learned with bipolar disorder, schizophrenia, trauma. So thanks for that. We'll be talking about that in a future [crosstalk 00:39:57]

Dr. Tom Insel (00:39:57):

Yeah. I should also say the proceeds from my book go to a nonprofit, which publishes a daily newsletter called MindSite News. S-I-T-E, MindSite News.

Dr. Ken Duckworth (00:40:08):

Excellent.

Dr. Tom Insel (00:40:09):

Mindsitenews.org. Check it out. It's a free nonprofit, nonpartisan, independent newspaper.

Dr. Ken Duckworth (00:40:16):

Nice.

Dr. Tom Insel (00:40:17):

Daily publication, which covers everything in the world of mental health.

Dr. Ken Duckworth (00:40:22):

Excellent.

Dr. Tom Insel (00:40:24):

So yeah, today we did a thing on what's happening in campus mental health.

Dr. Ken Duckworth (00:40:30):

Yeah. There's a couple questions about campus mental health. I wanted to, as a natural segue here, we have seen some very high profile deaths by suicide among some college athletes. Do you have thoughts about the pressures on kids? What campuses should be doing? What we can be doing?

Dr. Tom Insel (00:40:55):

Yeah. This is a place speed of how we need to change our expectations. Big, big need here. My last company was called Humanest Care, still very active. It works mostly in the university setting, building online communities of support for students so they can help each other. But it's helped me to learn a lot about what happens in the world of campus counseling centers.

Most counseling centers are open from nine to five, Monday through Friday. They close for winter break and they close for the entire summer break. Now, I don't understand how you can do that if you're a healthcare system and if you're there to prevent suicide or to help kids in need. I don't understand how you can run a system like that and tell people that they've got a 10 to 12-week waiting list before they can be seen.

So we got some work to do. This is a place where we talked a little bit before about technology. Ken you were asking about that? Humanest started off as a tech company, but we're one of many of these startups that are trying to take on this problem and innovate to fix it. It's not that hard to fix. I mean, there's a lot we can do here. But we've got to change the models. And yet when we've tried to work with the University of California system, there's a tremendous amount of resistance. They don't want anybody coming in from outside.

They're a union shop, so you got to be a union therapist. Lots of concerns about the counseling center in many places feeling threatened by startups or by the private sector. And yet we know how to scale care. We know how to get kids immediate access. We know how to solve most of these problems. So again, I think there's solutions here, but there are these structural barriers we're going to have to get past. I'm actually getting pretty frustrated with the state of care in a lot of the campuses.

We do have the Jed Foundation. We have Active Minds. We have these nonprofit groups that are doing great work. The MindSite piece today is about an Active Minds program that's worked well around the country. And I think the next phase of this is going to be getting those nonprofits to begin working with the for-profits that actually can provide care at scale and improve the quality of care.

Dr. Tom Insel (00:43:30):

I think we need to make that step in the next couple of years because no question, the need is great. When you look at the numbers, just before this phone call, another reason I was looking at numbers during COVID in the last two years for kids under the age of 30... I shouldn't say kids for adults under the age of 30, there were about something like 6,000 COVID deaths. There were probably 20 times that number... Well, over the two-year period, I think you could say two and a half years, probably about a hundred thousand suicides in that age group.

Well, in that age group, probably a little less than that, but still we're talking about probably five to 10 times more deaths, from deaths of despair, overdoses, suicides, alcohol related deaths in people under the age of 30 than COVID deaths. So we've got to get on top of this. It's gotten worse, not better. And I think part of this is going to require thinking differently about it and really bringing in the kind of innovation that's possible from the private sector.

Dr. Ken Duckworth (00:44:44):

Thank you, Tom. Let's talk about peer support and technology. You've done a lot of work in this area. And one of the things that I was impressed with, I've interviewed 130 people for the NAMI book, I had a chapter called the power peers, which I hadn't planned to do. When you listen to people peers make a tremendous difference for a lot of people. You've been able to scale technology ideas on how peer support might function. Can we tell a little bit about that?

Dr. Tom Insel (00:45:14):

Yeah. So this was a project that we did at Humanest. When I founded Humanest, co-founded it, I actually co-founded it with my daughter, who's a real expert and all this stuff, everything that we ended up doing was her idea, because she knows 10 times more about this than I do, but she had this idea that the biggest problem was engagement. And if we really wanted to... Those things are the five things I listed like capacity, and engagement, and quality.

I mean, she kind of bought into all of them, but she said, "Let's take this company forward just solving the engagement problem." And she began to realize that a lot of what we needed to do there was to meet people where they are and offer them support in the way they wanted it. And what became really clear was that for young people, they weren't buying what we were selling.

They weren't interested in the brick and mortar, 50-minute hour with a credentialed therapist. They really wanted peer support groups. They wanted to be connecting to each other on their own terms often with asynchronous group chat. So with the convenience and kind of open-ended interaction there. It had to be moderated. That was an important piece of what we learned with Humanest. But I'll tell you what to me most impressive was that a lot of people signed on to get help and they stayed to give help. That what was more engaging and honestly, more therapeutic than anything else was empowering somebody in enabling them to help somebody else.

Dr. Tom Insel (00:46:52):

We don't do that in healthcare, right? The whole system we have set up is you go to see an expert. The expert has the answers. They write a prescription. That's what we pay for.

Dr. Ken Duckworth (00:47:04):

You're doing at NAMI, but it's not really part of the healthcare system. I freely agree with you on that.

Dr. Tom Insel (00:47:10):

Yeah. Well, maybe we need to rethink that. I mean the Humanest model, which is work beautifully, particularly with university students is giving them a chance to help each other and doing it through technology and letting them meet online in a way that provides both the privacy and the tools to be able to be helpful.

Dr. Ken Duckworth (00:47:36):

Tom, insurance companies don't pay enough. That's a statement and not a question. That's how half a psychiatrist don't participate in insurance. That's why many therapists also don't take insurance. So let's talk about advocacy in changing that equation. So this gets into what is parity. So the parity law stopped people from having $500 a year in benefits and two admissions. But it didn't get to this question of payment. And it's not really a question, it's a statement. It came in a form of a question, but I'm just going to assert. Health plans don't pay enough to keep up with the private demand, ergo, what should we do about it?

Dr. Tom Insel (00:48:19):

Well, some of it. Well, Ken, I'm going to go bounce this back and forth. I mean, part of it, crassly, it's just money, right? They've got to decide that they're going to pay enough so that they can get enough providers within network. But there's another side to it, which is, I think we need to have a workforce that's willing to do all the things you have to do to get credentialed. We have to demonstrate that we have a workforce that's doing something that's worth paying for. We don't always have that.

Again, I think there's issues on both sides, but what I think is most egregious here is that we do have a pretty good law. I think the parity law from 2008 covers pretty much the issues that we needed to. It's just not been enforced. And that's finally beginning to change with new administration. Marty Walsh, who's from Massachusetts there is the new secretary of labor. Not so new. He's been in there for over a year. But Secretary Walsh has said very clearly going forward with backing from congress, they will begin doing unannounced site visit to actually assess whether parity is in place at large corporations. And their first 10 site visits, they were batting zero for 10. They didn't find anybody who was actually following the spirit and the letter of the law. And there will be penalty.

Dr. Ken Duckworth (00:49:55):

Once there's private pay radiologists and cardiologists who refuse to accept the reimbursement, then we'll be on the same footing because we aren't there now.

Dr. Tom Insel (00:50:06):

Yeah. So I think that's the part of it that is like just increase the reimbursement, but they're going to have to build out those in network provider groups and right now they don't exist. The numbers are for mental health, it's five times more likely that you'll need to go out of network than for physical illnesses. Five times more. I mean, that is pretty astounding. So there's a lot of work to do here. And a lot of it begins with enforcement of the law that we've got.

Dr. Ken Duckworth (00:50:37):

One of the things I will say, I worked at a health plan because I wanted to understand this game particularly well. The last thing you want to do is file an appeal. I'm going to encourage you to take the time and file an appeal because health plans speak the language of paperwork and regulation. And in every state, there's some independent body, which is overlooking the health plans decision-making. And that's one of the ways to get change.

Attorney generals, division of insurance. These are all bodies. And the last thing you want to do is fight with your health plan because all you want to do is get help. But I'm just here to tell you it's one of the gigs I did in my continuing education, misadventure of my career was I wanted to see how it worked and I know now how it works.

Dr. Tom Insel (00:51:25):

If you're looking for that catalytic point in these pathways go to your third-party administrator if you work for a big employer and find out... How closely are they checking on access? How closely are they checking on network sufficiency? And those are questions they should it be forced to answer.

Dr. Ken Duckworth (00:51:49):

Right.

Dr. Tom Insel (00:51:50):

Often they don't.

Dr. Ken Duckworth (00:51:51):

Well, we call him Mattie Walsh here in Boston. So I'm hoping Mattie can apply some activity.

Dr. Tom Insel (00:51:57):

Okay.

Dr. Ken Duckworth (00:51:59):

So let's talk a little bit about... Let's keep shifting gears. Let's talk about rural mental health. In your travels. You did a lot of your field research, if you will, pre-pandemic.

Dr. Tom Insel (00:52:12):

Yeah.

Dr. Ken Duckworth (00:52:14):

You traveled to-

Dr. Tom Insel (00:52:14):

Yeah. All of it was...

Dr. Ken Duckworth (00:52:14):

You traveled to Fountain House. The first clubhouse in America from the 1940s in New York City. You traveled to the amazing setup in Los Angeles for recovery. You did the tour of America. Did you go to rural places? What is your take on telehealth as a potential solution? And of course, telehealth exploded in the pandemic. What is your take on that?

Dr. Tom Insel (00:52:39):

Yeah. So I'm super bullish on telehealth, but I think we're early days, right? So it has solved some problems. It's improved, what I call the democratization of care. So it's improved access. It doesn't matter whether you live in a rural or an urban area, you can still access someone within state because you can't cross state lines. But that's pretty cool. I mean, that's a really important thing to have. And now with the regulations as they are, you don't have to see somebody in person to get reimbursed or to get insurance coverage for a telehealth visit.

So that's good. What I worry about is not so much the access problem, but the quality problem. It's not clear to me that moving to telehealth has improved the quality of care, but it could. So where I want to go is what I talk about a lot is telehealth 2.0. Getting to a point where we use the telehealth interview to collect data on how people are feeling.

Some of that could be passive, but a lot of it I think is to make sure that every telehealth visit has a PHQ-9 or a GAD7 or some kind of patient reported outcome built into it. So we use measurement based care as part of the telehealth revolution. It hasn't happened yet. And if we don't measure, we don't manage, right?

Dr. Ken Duckworth (00:54:09):

PHQ-9 is the patient health questionnaire nine, free valid. It's the closest thing we have to blood pressure for depression. Would you agree?

Dr. Tom Insel (00:54:19):

Yeah.

Dr. Ken Duckworth (00:54:19):

The GD-7, same thing for anxiety. It's the closest thing we have to blood pressure because we don't measure things in mental health. It makes it hard to know if we're doing better. When I was trained, it was like the patient feels better to me. Well, that's great. But what about their PHQ-9 score which is also might be helpful with reimbursement because we can say we're measuring something like blood pressure. You can track people's progress. Would you agree?

Dr. Tom Insel (00:54:47):

Yeah. I think eventually we want to do better than the PHQ-9 because it's not great. It takes what 50 seconds or something to fill it out. It's quick. It's valid. It's not ideal. I mean, eventually you want to be able to measure things that matter to people. So it's not just a mood symptom score, but are you back at work? Are you taking care of your kids? How are you sleeping? We ought to be monitoring sleep. We ought know. We ought to be able to measure how people are sleeping instead of just asking them.

Even with something like tremor, we ask people, how's the tremor, but we're not actually measuring tremor when we know how to do that. I mean, there's a lot of stuff we know how to measure, activity, social interaction, all that stuff.

It's not that complicated. We don't just have to rely on subjective reports. And so what I want for telehealth 2.0, whether it's rural or urban is that we start to build in measurement based care and that's how we're going to improve quality. That's how we begin to improve outcomes. By the way that's happening, in some places. They're doing a great job.

There's a company in the UK called Ieso. They're not in the United States yet, but they work with the National Health Service. They treated hundreds of thousands of people for depression, anxiety, online CBT. And every session has this kind of built-in passive measurement with a dashboard. It tells people not only how they're doing, but how's our relationship going in terms of therapists to client? What's our rapport like? Are you hearing me? Am I hearing you all that stuff? It's pretty cool.

And they've done it with just brilliant AI and with data science in a way that's not intrusive. And they've been able show that when you measure and you get the feedback, the outcomes get better. Bingo. So we know this works. We need to start doing it.

Dr. Ken Duckworth (00:56:50):

Big cultural challenge there in a field that has historically resisted measurement and has embraced the subjective. So I see the challenge there and I'm happy to do the best I can to support that endeavor, because this definitely relates to reimbursement questions.

Dr. Tom Insel (00:57:08):

Totally.

Dr. Ken Duckworth (00:57:09):

Tom, last question I have for you and I just want to say it's been a great conversation. There's very few people that can talk about the entire waterfront. Where do you see the science going? You mentioned the brilliant and how it hasn't really translated to people as much as we would want. Where do you see the most promising corners of neuroscience?

Dr. Tom Insel (00:57:35):

Yeah, I think we have to do better on diagnosis before we do better on therapeutics. One of the things I do is I study what's worked elsewhere. I've always done that in everything I do. I study success and right now we're having a lot of success in breast cancer and we're having a lot of success in other cancers because we've gotten much smarter about diagnosis.

In fact, we don't use the term breast cancer. We would say, "Well, it's a HER2-positive, PR-negative, ER-positive breast tumor. And that's allowed us to know which treatments are going to work for that particular tumor because we understand how to make that actual precise diagnosis. So this field of precision medicine, we're just starting to do that. And I think the science is helping us. There's no magic here.

There's not like a single thing. People thought that genetics or imaging was going to do. Doesn't work. What does seem to be helpful is taking people who have a mood disorder and understanding a bunch of things about them. So understanding some social factors, understanding how they think, so the cognitive deficits. Beginning to look at you can use an EEG, you can do this at home. We can collect the EEG at home and it works really well.

Amazingly that is helping us to figure out what patterns seem to go with which treatment responses. But you put all this together. You put together some wearable data, the symptoms they have, some social factors, issues around EEG, some cognitive data and you start to build out a description. Sure enough, it turns out that depression isn't one thing, it's biologically in terms of therapeutics probably four or five different syndromes.

We have to get better at that. And I think the sign is taking us there really quickly. I just did an event this morning with Amit Etkin who founded Alto Neuroscience. It's totally what they're doing. Their whole company is working on this problem. It's pretty stunning how quickly this is moving. How already for PTSD and depression, he's able to define very clear subtypes that have a very specific relationship to treatment response. That's pretty awesome.

Dr. Ken Duckworth (01:00:13):

Pretty amazing. And the accelerated medicine partnership, AMP schizophrenia, which NAMI was part of jump starting is $100 million project on psychosis trying to understand biological markers. But not simply things that you can draw from a blood sample. Again, it's EEG. It's imaging. It's social interviews. It's this whole composite to get to a more personalized approach for psychosis treatment, which we don't have either.

Dr. Tom Insel (01:00:43):

Yeah. That's great.

Dr. Ken Duckworth (01:00:43):

So Tom, I just want to thank you for your time, for your expertise, for all your great work. It was wonderful to have you. And I'm going to turn this back over to **Dan Gillison**, our CEO.

Dan Gillison (01:00:56):

Thank you, Ken and thank you, Tom. It was very good to listen. And I've often said to Ken, we don't want to lose him to CNN and him being on one of those evening shows doing interviews with all this incredible talent across America. So thank you, Ken. And what you're seeing on your screen now is Healing: Our Path from Mental Illness to Mental Health from **Dr. Tom Insel**. It's a great read. It it gives us... Our values here at NAMI are inclusion, empowerment, compassion, fairness, and hope. And inside of Tom's book, it gives us hope.

It takes us from hopeless to hopeful. So if you have not, please pick up Tom's book. And thank you for sharing with us today. Tom, I also enjoyed the comment about go from the word stigma to the word discrimination. We can actually operate on something like that. And as well as what your daughter shared with you about engagement. Our young people want engagement. What I'd share here is something as we get ready to go to this next book real quickly to this audience.

Thank you for everyone and staying with us. As we talk about engagement, our young people, also many times trust technology more than they trust the experience with a human being because they've grown up with technology. To that point, if you are on the Siri platform and you engage Siri, and you say, "I am feeling depressed," see what comes up. I will challenge you. It gives you the opportunity to connect with a friend or family member, and then if not to connect with NAMI.

So now the next book, this is NAMI's first book. And this book, as Ken talked about, he interviewed over 130 individuals, real individuals and their families, and this has expert advice and wisdom. And it's peer to peer from a standpoint of a peer going through something in this book, You Are Not Alone: The NAMI Guide to Navigating Mental Health. So you can pre-order the book now on Amazon. And we would offer to you and suggest to you for you to do that.

And I just also want to say to Ken, thank you for lending your expertise to us, Ken, and honoring us with this book. We really do appreciate it.

So now let's talk about the next ask the expert. It is on Thursday, the 26th of May from 4 to 5:30 Eastern Standard Time. And it will be the History of 911 and Lessons Learned for 988 and Dr. Rebecca Neusteter principal investigator for transformed 911 and executive director for the University of Chicago Health Lab will be there. Interesting thing about 911 started 50 years ago.

Dan Gillison (01:03:43):

First two calls were made in 1969. One was in Mobil, Alabama, and the other one was in Nome, Alaska. So we got a long way to go. We can't rest on 50 years for 988, but we also understand lessons learned on 911, which is that there there are voices that went at the tables in the design of 911 that we need to make sure are at the table as we design out 988. So there are absolutely some opportunities inside of that.

So as we look at this, the other thing we want to mention to you is our NAMI convention this year. This is the 14th through the 16th of June together for mental health. We are strongest when we join together. And what we're creating is a tapestry, a quilt, and there's a common thread through it. There's one thread through a quilt and every one of those patches, as you think about a quilt has this thread through it. And that thread is our thread of mental health and it's going to take all of us.

So together for mental health. Please join us the 14th through the 16th for our convention. And we really do appreciate you. Remember, you are not alone. And as we spoke about our young people on today, and as we recognize what needs to happen in that space and what Tom shared with us that the story they did on MindSite news on today, we've got to sure all of our young people know that they are not alone.

And I'll ask the expert. We just want to make sure you have this footnote. It's an informational webinar series, and it's not intended to provide a medical device on any specific topic or for any specific individual. The series is made possible through the generous support of people like you. So if you are enjoying these free programs, please consider donating to nami.org/donate. And we appreciate you very much.

And in the wrap-up, none of this is possible without incredible support and incredible teamwork. So we want to thank the production team, and that production team is Jordan Miller, Zahira Correa, Divanna Eckles, and Jessica Walthall. Again, none of this would happen without this incredible team that does all of the work by behind the curtains before we open them, and we start this.

To all of you that are making a difference in the communities that you're in, we would challenge you to continue to do that. Thank you for doing it. And also remember that you've got to do self-care to help others. So make sure you're taking care of yourself as you help others. Remember to engage and let's do everything and we can to help each other and the communities in which we serve. We appreciate you. Have a great close to your Thursday and a wonderful weekend.