Dr. Xavier Amador Shares His Experiences Addressing Anosognosia

Jennifer Cohen and Xavier Amador

Jennifer Cohen 0:04

Welcome to the Voices and Bioethics Podcast. I'm Jennifer Cohen and it's my great pleasure to welcome renowned clinical psychologist researcher and author, Dr. Xavier Amador, to the podcast. Dr. Amador, thank you so much for joining us today.

Xavier Amador 0:20

You're very welcome, Jennifer. Great to be here.

Jennifer Cohen 0:22

Dr. Amador, from 1989 to 2002 you were on the medical school faculty at Columbia University College of Physicians and Surgeons, where you served as a professor of psychiatry and clinical psychology and director of psychology at the New York State Psychiatric Institute. Following your time in academic medicine, you accepted a position as director at the Center for research, education and practice at the National Alliance on Mental illness. Your best-selling book, "I Am Not Sick, I Don't Need Help! How to Help Someone with Mental Illness Accept Treatment" celebrated its 20th anniversary of publication last year. You're the author of more than 120 peer reviewed articles. Your expertise has been called upon by government, the healthcare community and the broadcast and print media. And you appear as a frequent guest and expert on CNN, ABC News, NBC News, Fox News, CBS 60 minutes, New York Times, Washington Post, USA Today, Wall Street Journal, and many other national and international news outlets. Currently, you're serving as the CEO of the Henry Amador Center on Anosognosia. Before I ask you why the center is named Henry Amador and what anosognosia is, I want to first ask you a few questions about your background and decision to become a psychologist. Where were you born? And where did you grow up?

Xavier Amador 1:40

I was born in a little town called Sancti Spíritus, in Cuba. And as you mentioned, I am a clinical psychologist.

Jennifer Cohen 1:47

How did you decide to become a psychologist? Did you come from a family of healthcare providers?

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Xavier Amador 1:53

My family does not have any healthcare providers. I am the one and only. My interest in becoming a clinical psychologist actually came from reading a book when I was 14 years old, called "On becoming a person" by Carl Rogers. And as we talk further, I'll be talking a little bit about the L.E.A.P program. And how many aspects of that program come from Dr. Rogers approach to doing psychotherapy. So I read that book and I thought, this is what I want to do… I really don't have a lot more insight about that other than how appealing the book was to me in terms of understanding people and the importance of relationships, in the practice of psychotherapy, and the value of creating a safe place for people to talk.

Jennifer Cohen 2:38

Yes, I want to unpack all of that. As I mentioned in your introduction, you are currently the CEO of the Henry Amador center on anosognosia. Why is the center named for Henry Amador?

Xavier Amador 2:51

Well, Henry was my brother, we were very, very close with each other for really our entire life until he developed schizophrenia in his 20s. And that began a seven-year period where the two of us really butted heads and argued a lot. And the argument centered around me saying Henry, you're mentally ill. You are hearing voices, you've got strange ideas, you need some help. In him saying to me, I'm not sick, I don't need help. You're the crazy one, not me. And my attempting to, you know, educate him trying to convince him that he needed psychiatric help. We fought and argued for seven years, sometimes softly and with compassion and kindness on my part, and other times with frustration and anger on both our parts. And later, I learned during my training to become a clinical psychologist, how to stop talking and start listening. And that was huge. It sounds simple. It sounds kind of straightforward. But when you have an agenda, like I had tried to get my brother help, it wasn't so straightforward. And long story short, is through using a lot of the techniques that are now embedded in the late approach to talking with people with mental illness, who don't understand they're ill. I realized that I had to approach my brother in a different way. And I called him up. This is after seven years of arguing and I apologized. I told Henry I was sorry for telling him he was mentally ill. I was sorry for telling him he needed psychiatric medications. And I promise never to do those things again. That led to his accepting antipsychotic medication for the rest of his life-. Long acting injectable medication, he would just show up for an appointment and get an injection. And he went from three to four hospitalizations a year. No work, no girlfriend, no friends, no school, to recovery, to having all those things back. So Henry passed away. He was actually in the middle of an aact of being a good Samaritan. He had gotten on a city bus. This is in Tucson, Arizona, and saw a woman struggling with her groceries. So he stepped off the bus. She stepped on, he was passing her groceries to her, when a driver lost control of his car and ran up onto the sidewalk. So my brother didn't die from his illness, he didn't die from suicide. He had schizophrenia. He died being the good guy that he was, you know, helping another person. But… the really… the thing I guess, I'd like to say about Henry is that he accepted treatment, despite the fact that he never, ever believed he had a mental illness. He accepted treatment, really, because of our relationship. And that's what he said, point blank. When I asked him one day, I said, I give a lot of talks, I talk about you, and he knew that. I said, "Do you think you're mentally ill?" He says, "No, I don't think there's anything wrong with me." And I said, "Why are you taking these injections?" And he said, "Well, I do it for you." So that story was very powerful for our board of directors. And we

didn't used to be called the Henry Amador Center on anosognosia. We had a different name, but the board felt we should honor Henry and the example that Henry is, of how relationships can lead to acceptance of help and ultimately to recovery.

Jennifer Cohen 6:25

Such a powerful story. Before my next question, I want to clarify for the audience. So when the word schizophrenic is used in colloquial English, it's often meant to convey sort of a violent flip flopping between two opposing contradictory positions. But that bears little relation to the neurological disease of schizophrenia.

Xavier Amador 6:47

Correct. There's no relation, actually, you hear in the media all the time in the entertainment media. Oh, that person's being schizophrenic. That has nothing to do with the brain disorder of schizophrenia.

Jennifer Cohen 6:58

Yeah. Okay. So as you said, it's the Henry Amador Center for anosognosia. What is anosognosia?

Xavier Amador 7:06

Before I answer the question, I have to tell you, I fought with the board of directors of the Henry Amador Center. I said we should just call it the Henry Amador Center, because anosognosia is a tongue twister. It's really hard to pronounce. But they convinced me because part of our mission is to educate people about this symptom of serious mental illnesses. And when I say serious mental illnesses, a lot of mental illnesses are very serious. But the ones that we're focusing on in our center are psychotic disorders, schizophrenia, delusional disorder, Schizoaffective disorder, bipolar disorder. And people with these disorders, half of them, it's a huge proportion, half of them have a symptom called anosognosia, which is a symptom of their brain disorder that renders them incapable of understanding they have a mental illness. So, it's not denial. It's not stubbornness. It's not immaturity. It's not denial. Let me say that, again. It's another symptom just like a delusion or a hallucination. That leaves the person blind, literally blind, to the fact that they have a serious mental illness.

Jennifer Cohen 8:20

You say that the center has a mission of education, which is wonderful. And why have most people myself included before I read your book, not heard this term before, even though, as you explain in the book, it's been in the DSM for 15 years as a symptom of schizophrenia and other psychotic disorders?

Xavier Amador 8:40

Well, actually, it's been in the DSM, the previous DSM since the year 2000. So 21 years. The reason is because

there's a very natural gap between science and practice. And by practice, I mean, what healthcare professionals learn and do, but also what family members like myself, find out about, there's a very natural gap between scientific discovery, many of them, especially in the behavioral health realm, and that trickling down to the people who really need to know about the science.

Jennifer Cohen 9:16

So physical illnesses are normally diagnosed when a person develops symptoms, reports them to their doctor, when a person has little to no recognition that they are experiencing symptoms. This must present clinicians with incredible challenges in determining a diagnosis. How does anosognosia affect the ability of clinicians to accurately diagnose people?

Xavier Amador 9:39

If they're not aware of anosognosia it destroys their ability to accurately diagnose because what happens is somebody who's delusional for example, about the CIA monitoring them, or that their family is involved in a conspiracy against them and then they go to the emergency room and they know what sounds pardon the expression but they know It sounds crazy. So they typically, I've worked with many people like this. And I do the same thing if I was in their shoes, they don't talk about that with the doctor. Because they know if they do, the doctor will admit them to the hospital. And they're, you know, absolutely solid belief is there's nothing wrong with me, I don't need a hospital, and so they hide what they believe other people will see as symptoms. So the short answer to your question, Jennifer, is that for doctors, you're talking with someone who doesn't want to tell you about really important symptoms, because they don't see them as symptoms. And by the way, this is why it's really important. And appealing to any healthcare professionals, social workers, nurses, doctors, psychologists, that you talk to the family, that you get what we call collateral information. Because the family can shine a big bright light on the person that you're talking to and tell you about the fact that they've been sleeping in their car naked, or that because of the radiation they're getting from the aliens or and that's a real case, a real situation I'm working on with the family right now. They can tell you about the symptoms of mental illness. So as a doctor, as a healthcare professional, please talk to the family, their critical source of important information that you will not get from the person who has anosognosia.

Jennifer Cohen 11:29

And how does anosognosia relate to the bedrock principle of bioethics and medical ethics that have autonomy, which is usually understood to be informed consent where a patient is given as full information as possible in order to weigh risks and benefits of treatment and medication? How does that process be adapted to patients? With anosognosia?

Xavier Amador 11:51

It's a really great question and by great question. I mean, it's really at the crux of a lot of tragedy. What impact it has is that the person with anosognosia for mental illness really, from my perspective, I'm not entirely alone in this

perspective, doesn't have the capacity to make healthcare decisions for themselves, because they don't believe anything is wrong. Anything is going on that requires treatment. So they are really, by definition, if they do have the symptom of anosognosia, incapable of seeking treatment, and let me put it a different way. If you were to believe we had a mental illness. Many would say it's our right to refuse treatment. But is it really? Is it really? If it was somebody with Alzheimer's and a lot of people with Alzheimer's do go through periods of anosognosia, we treat that person even though they don't want to be treated. So it's a very… it's a tricky area, because we're talking about people who, with mental illness, who can be articulate can be cogent, but they still have serious symptoms of mental illness that lead them to hopelessness, suicide, homelessness, and do we really want to just leave them alone with these very serious brain disorders that are life threatening?

Jennifer Cohen 13:16

And you've mentioned the reasons why your brother decided to stick with medications. And your book emphasizes some really startling statistics around the rates of mental health patient non compliance with treatment, the numbers of mentally ill people who are prescribed medications, but don't take them or don't take them as prescribed. You write that most studies find it's somewhere around 50%, sometimes up to 75% of people with serious mental illnesses that are not taking their medication. So many people think that patients don't take their medications because they fear side effects. But you've done some really interesting research that has come to different conclusions on that. Can you discuss that?

Xavier Amador 13:55

Sure. And let me emphasize our research group, we're not the only people who have done research on this. There's a lot of research that comes from around the world. That indicates that side effects in negative experience have side effects, doesn't actually impact someone's refusal of medication. The term we use is compliance or adherence. Side effects are very important, don't get me wrong, we need to address them lower doses when somebody has side effects that really, really troubled them or endanger them, or try a different medication that is more likely to not produce those side effects. But side effects are not the reason people refuse treatment or drop out of treatment. The research is really well replicated and abundantly clear. That the number one reason people with these serious mental illnesses, refuse medication, or drop out of treatment once they start is anosognosia. Anosognosia is the number one treatment and to put it in layman's terms. Let's just remember, the person is unable to see or understand that they have a mental illness.

Jennifer Cohen 15:08

I think I remember you writing that many times, side effects are brought up, because that is the one type of discussion they know they'll be heard on. And it's just a very poignant fact that that's why they might be bringing them up.

Xavier Amador 15:23

Yeah, look, let's say I'm in the hospital, I've got schizophrenia, and I have anosognosia. And I don't want to be on

medication, what's the one thing my nurse or my doctor is going to listen to? They're not going to listen to me saying "I'm not sick, I don't need this," they're going to listen to the side effects. So what happens is many people with anosognosia, learn how to speak the language of the healthcare professionals, when what really needs to happen is we need to learn to speak the language of the person with mental illness.

Jennifer Cohen 15:53

Another fascinating misunderstanding of this issue of insight that you discuss is the assumption, which is not, you know, wholly counterintuitive, that if the patient understood how ill they are, they'll become even more depressed or even suicidal. So in some sense, this lack of insight might be protecting them. But what did your research show?

Xavier Amador 16:16

Research shows that that's a myth. Awareness of being ill or insight does not increase the likelihood that someone will be suicidal.

Jennifer Cohen 16:25

Okay, let's transfer into a discussion about the L.E.A.P method by this question. How can an understanding of anosognosia as a symptom of mental illness, not as denial, as you say, help family members with issues of frustration and even anger that they might be feeling?

Xavier Amador 16:44

Well, once you understand the root of the problem, and that it's not that your loved one is being difficult or stubborn, or in denial, or grandiose, right? All those pejorative ideas that I held when my brother first became ill, and you understand that instead the problem is another symptom of the brain disorder, just like the delusions or hallucinations we are seeing. Then it kind of pulls you up short, and you think, well, I can't educate this person, you can't talk somebody out of a delusion. Same thing, you can't talk somebody out of their anosognosia, they don't understand they're ill. Any amount of confrontation, intervention, education doesn't work. So the L.E.A.P. method really grew out of a lot of experience, a lot of on the ground experience, trying to help people with anosognosia accept treatment. And one last thing I'll say, to answer your question, is that, you know, ask yourself the question: "Have you been able? For how long have you tried to convince your loved one, they're mentally ill. And if it's been six months, or a year… I've talked to families where it's been 15-20 years… ask yourself, have I been successful? And if the answer is no, and it will be no, if your loved one has anosognosia, because it's a long-term, long-standing symptom, then I'll speak for myself, I was insane. That was insanity. If, you know, we remember Einstein's definition of insanity, doing the same thing over and over and over again, and expecting a different result. That's what I was doing. So understanding that it's anosognosia, rather than denial, changes your whole approach.

Jennifer Cohen 18:39

Now, you're right that L.E.A.P. grew out of motivational enhancement therapy, can you tell us what that is, and

how it developed into the leap method, and what the four elements of the L.E.A.P. method are?

Xavier Amador 18:52

Well, the part that grew out of motivational enhancement therapy or motivational interviewing is the collaborative approach where you're really trying to focus on the problems the person sees that they have, rather than impose upon them the problems that you believe they have. So that's the part that comes from motivational interviewing. When we started this conversation, Jennifer, I mentioned the book on becoming a person by Carl Rogers, where he was the founder of the humanistic movement. And L.E.A.P. also draws from that movement. It's also called client centered therapy. So the motivational interviewing part is the collaborative approach. The part that comes from client centered or humanistic psychotherapy is the creation of a relationship where the person feels that you really care about them and that you're not, and that this is important. You're not judging them for their beliefs. And instead, you're being very respectful of their beliefs. And there's a third school of thought, which is cognitive behavioral therapy. And that's very collaborative as well. You set agendas, you look for areas where you agree with the person. So I'm remembering an interview with Woody Guthrie, the author of "This land is your land," right? He was asked, or he was accused rather in an interview I read, of stealing traditional gospel hymns. You know, aren't you just stealing traditional gospel hymns? And his answer was, Well, yeah, I am. And then they asked why and Woody Guthrie answers, because all the good melodies have already been written. And I'm not putting myself in the same level as Woody Guthrie. But basically, the L.E.A.P. approach is the same. Well, you know, we're utilizing a lot of the psychological melodies that have proven to be very effective in gaining people's trust and helping them to change.

Jennifer Cohen 20:51

Okay, so the L in L.E.A.P. stands for Listen.

Xavier Amador 20:56

It's not your everyday form of listening. L.E.A.P. reflective listening is listening without judgment, listening respectfully and listening actively. So if you were to tell me, let's say you had bipolar disorder, and you were telling me that there's nothing wrong with you, you've never had bipolar disorder, you were misdiagnosed. I would say, well, Jennifer, what you're saying is, you don't have bipolar disorder, and that they misdiagnosed you, did I hear you correctly? That's an example of L.E.A.P. reflective listening. If somebody tells me that there's an alien transplant in their brain, I would say. So what you're saying is that there's an alien transplant in your brain, and that's causing the voices you're hearing. Did I get that right? So the reflective listening starts with the preface "Let me see if I understood. Tell me if I got this right." You then reflect back what the person said. And then importantly, you check in with them to find out if they felt heard. Did I get that right? Did I understand you?

Jennifer Cohen 21:56

And the E stands for empathize.

Xavier Amador 21:59

And L.E.A.P. empathy is also a little bit different than everyday empathy in that we're being strategic, we're making sure that we empathize with those feelings that stem from the anosognosia or from delusions. "So you sound really frustrated and angry about the fact that your parents are saying that you're mentally ill, are you?" "Yeah, I'm furious. I'm really pissed off about it." And then part of L.E.A.P. empathy is you normalize the emotion. "You know what, I'd be angry and pissed off too. Anybody would be." Now some people might, a lot of people over the years have said, "Well, wait a minute, aren't you kind of agreeing with the person?" And you're actually not when you're using L.E.A.P. reflective listening, and that strategic empathy, what you're doing, like in motivational interviewing, and client centered therapy, and cognitive therapy is that you're joining the person where they are. You're embracing their experience, you're respecting it. You're not saying I agree that you don't have bipolar disorder, or I agree, there's an alien transmitter in your brain, you're doing something very different.

Jennifer Cohen 23:08

So the A stands for agree. "What are you finding common ground and agreeing on, then?

Xavier Amador 23:14

All kinds of things. And the first step to using the and we call these tools, these are not steps, let me be really clear. And what I often ask people to do when we're training people in L.E.A.P. is, imagine a tool belt, and you've got all sorts of communication tools on one side of your tool belt and on the other side, I asked that you imagine seven empty pockets. There's actually seven tools. There's the four main ones, which is listen, empathize, agree and partner. Now the agree tool involves first and foremost giving up on agreeing that the person is mentally ill, if they have anosognosia. They're not capable of understanding they're mentally ill. So you don't want to focus on that. What you focus on are the things you actually can agree on. Things like we both can agree that staying out of the hospital is a good thing. Or many people I work with, with serious mental illness, say, I just need a job and a girlfriend, what Freud called the fundamental need for love and work. So we can agree on those things. We can agree on finding a job, getting money, having freedom, not arguing with your parents anymore, or your family or your brother, in my case. There's many, many things we can identify that we agree on. And that leads to – I'm going to preempt your next question – What does partner mean? And the P stands for partnering. And what we're partnering on are those things that we agreed on. So for example, what are the best ways for you to stay out of the hospital? What can we partner on to help you find a job or get housing that's stable? There's all sorts of things that we can talk about and partner on and collaborate on together.

Jennifer Cohen 24:54

You've alluded to it but let me ask you again about what some people might see as a potential ethical issue. How do you answer people who say, "look, I can't stand by and listen to false delusional beliefs, and engaging in conversations about delusions is a form of lying and enabling, and it ends up reinforcing the delusions, and I can't do that."

Xavier Amador 25:17

I say to the people who say that to me, and I hear it all the time, is, then you're leaving the person alone. You know, the L.E.A.P. approach is about creating a connection with somebody who is incredibly alone. They believe things that nobody else believes, and their life has changed in ways they never anticipated. They're not working, they don't have a boyfriend or a girlfriend or a husband or a wife, they don't have kids, they see their friends, who are the same age, quote, "moving on with their lives." And they're not in there alone. So listening, respecting, not judging. What they do want to talk about, is really the only way to build that bridge to this very lonely person.

Jennifer Cohen 26:05

And as you say, you're not agreeing that the delusion is correct.

Xavier Amador 26:10

That's right. That's right. And let me add one thing, if you're using this approach, the L.E.A.P. approach, you're being 100% honest. You're not saying "so what you're saying is that you have an alien transmitter in your brain. And yeah, I see that you do." That would be agreeing with the person.

Jennifer Cohen 26:21

Right.

Xavier Amador 26:22

…or "You're saying you're not mentally ill? Yeah, I think that's right." That would be agreeing with the person. No with L.E.A.P. reflective listening, for example, or empathy, you're asking the person, let me see if I understood you, you're not mentally ill. Did I get that right? Well, how do you feel about being in the hospital? I'm very angry about it. You know, I'd be angry too, anyone would be, and then the person will often ask you, well, what do you think? Do you think I'm mentally ill? And that's when we use the last three tools in the leap tool belt. You try to delay giving those contrary, conflicting opinions that are going to injure the relationship. And we use the three A's, as we call them. We apologize, for our opinion, we acknowledge our fallibility, we could be wrong. And we ask the person to not argue, agree to disagree. So how that sounds is something like this. Somebody… I've worked with people in the psychiatric units, and they say, "well, do you think I should take the medication?" And I'll try to delay giving that opinion. And the reason, by the way, is because not only do I not want to injure the relationship, I want more opportunities to reflectively listen and empathize with the person. So I might say something like, what you've asked me several times now, do I think you should take the medication, I want to apologize, my opinion might be disappointing, or frustrate you. And I could be wrong about this. I think trying the medication is a good idea. And I don't want to argue about it. I respect your opinion about this and I just hope you can respect mine since you've asked me. So that's another reason we delay giving our opinion is we can keep saying you've asked me for my opinion. And it's a solicited opinion, not an unsolicited opinion.

Jennifer Cohen 28:12

As we discussed, the ethical principle of autonomy is traditionally in a rights-based paradigm based on information sharing and voluntary consent, and you've constructed a variation on that model based on relationship-building, trust, respect, also vitally important ethical principles. Do you see the L.E.A.P. method also being of use in clinical medicine outside of mental health?

Xavier Amador 28:38

Oh, absolutely. In fact, I have another book called "I'm right, you're wrong. Now what?" And in that book, what I write about are lots of different circumstances where you can use L.E.A.P. working with all kinds of medical conditions and psychiatric conditions. The reason I wrote that book is that many people that came to L.E.A.P. trainings for mentally ill patients or loved ones, came back to me over the years and said… "Hey, can I consult with you about my patient with Alzheimer's? Or can I consult with you about my difficulties with my husband, or my teenager, or my boss at work?" And a lot of the work I did with those people was, you know, implementing L.E.A.P. in all of those different circumstances.

Jennifer Cohen 29:21

Now, you're clear in the book that the L.E.A.P. method does not obviate the need for involuntary admissions, in some cases. All 50 states have laws that permit citizens to be involuntarily committed under certain circumstances, usually when they're posing a danger to themselves or others. That is, they're suicidal or homicidal or when they can no longer care for themselves. And involuntary commitments are by definition coercive, and they can be traumatizing for patients and for their loved ones. You discuss in the book, the hesitation we have in American society to infringe on individual rights and freedoms and that that has resulted in major obstacles to getting the seriously mentally ill the treatment they need. You've already touched on it a bit. But can you elaborate on that and when it is ethical to override autonomy?

Xavier Amador 30:10

My view is, it's ethical to override autonomy if the person is unable to comprehend their medical needs, and the result of that is not just dangerousness to suffer. I think our involuntary treatment laws should be broader. Also, in circumstances when there's grave disability, when people choose homelessness, or they won't eat certain foods, and they end up with malnutrition, and they won't eat certain foods, because they have a delusion about the food being poisoned, for example, I've worked with people like that. So sometimes the L.E.A.P. approach doesn't work and we do need to consider and implement coercive treatment. My view of that, my comfort with that, comes from the understanding that if we don't – let's call it what it is, forced treatment on someone – if we don't force that treatment, this person is going to end up homeless or in our criminal justice system. Because oftentimes, when people are psychotic or grandiose and manic, they'll break the law. They'll do all kinds of things. I had a family I worked with where their son was firing a BB gun at office windows, he ended up with a third-degree felony. And the reason he was firing a BB gun at this particular office was because these were people who he believed, because he was delusional, were persecuting him. So should he have been in jail? Should he have a third degree felony on his record? And this is a young man who was in law school. And once he was in treatment, and in recovery, went back to law school, but he is incapable of passing the BAR and getting this law license because he

has his third-degree felony on his record. So that's just another very specific example of why coerced treatment could have been a tremendous help to this young man. Had he, before he started firing a BB gun at these office windows, been forced into treatment, the delusions then ameliorated and not driving his behavior, he wouldn't have this felony on his rap sheet.

Jennifer Cohen 32:23

You ask about confidentiality, and how that works. When a loved one is in the hospital, dealing with mental health issues of a loved one is enormously taxing. It's exhausting for families, once a loved one is in the hospital, the tendency might be to take a break, let the professionals take over. And in fact, you write in the book, the system is set up to put a wall between mental health professionals and their patients' families. How can families stay involved, if your opinion is that they should, especially given the strength of HIPAA protections around patient confidentiality?

Xavier Amador 32:58

You're raising two, again, I think, very important points in your question. One is, should you relax and sort of leave it in the hands of the professionals? And my very strongly held view is no, no way. The reason for that is if your loved one has anosognosia, they're going to very likely tell the professionals there's nothing wrong, oh, my mom said I had this hallucination or this delusion, but she was wrong, and I'm really okay. And the professional isn't going to treat your loved one. So that's the time you want to provide that collateral information I talked about earlier in our discussion. You want to be able to talk with the professionals and let them know just how ill your loved one is so that they're much more likely to be treated adequately, and not just released after three days, which happens way too often. Now, HIPAA is what you're referring to in terms of that wall, between a family member and the medical team, the doctor, the nurses, etc. Let me be very clear about this. And if anyone listening to us comes away with anything, I hope it's this when it comes to inpatient hospitalizations. If there's no HIPPA release, it's true. The healthcare team cannot tell you about your loved one. They will even say I can't even tell you if this person is here or not. But what you can do under HIPAA, and you need to educate the healthcare professional you're trying to reach by phone or by fax. And I get very specific examples in the work that I do with families about the kinds of faxes you want to send. And whether it's a phone conversation or a fax. You say, I realize you don't have a HIPPA release. I understand you can't talk to me about you know, john doe. I, however, know that you can gather information and listen. So here's the following information that I think is vital to John Doe's healthcare. And then you talk about the symptoms, you talk about the grave disability that your loved one is experiencing because of the symptoms, and you educate and inform the healthcare team so that they have a full picture of what's going on.

Jennifer Cohen 35:16

Okay, let's turn to some obstacles to mental healthcare delivering in the United States. And I want to pick up on a thread you mentioned earlier, we've discussed the fact that this symptom anosognosia, remains largely unknown to the public despite being a central part of serious mental illness. Can you elaborate on this gap that you mentioned in the findings of academic psychiatry and research and the knowledge base of general practitioners, the police, the legal system and the public? how that affects healthcare delivery? And what can be done to bridge

that gap?

Xavier Amador 35:51

Well, I'm going to answer that question first, with a very hopeful note, because of the work that the Henry Amador Center for anosognosia is doing. We've trained departments of psychiatry, clinical psychology programs, nursing programs, all over the country. And more and more often now, although it's still a minority, more and more often, we're seeing people diagnosed with anosognosia. I just worked with the family a couple of weeks ago, and they said, Well, our son was diagnosed with bipolar disorder and anosognosia. And I said, Wait, you actually heard anosognosia? And they said, Oh, yeah, it's part of the medical record that we were able to get because they had a HIPPA release. So things are changing. That's the good news. The reason things aren't changing as fast, as many of us would like, is first because of that gap between science and practice that I mentioned. But the other reason is that denial is intuitive, right? And we see it with substance abuse, people can oftentimes be in denial often are in denial of their substance abuse. So what do we do? We do interventions to educate them to help them feel loved, but to really kind of hit them over the head with how they've been abusing alcohol or drugs. So it's intuitive, you know, I've got somebody with schizophrenia or bipolar disorder, who doesn't understand they're ill, they're in denial, and I got to educate them and basically verbally wag my finger at them and say, you've got to understand this is a problem that you have. So it's still taught in training programs, partly because it's intuitive. The other reason is psychoanalysis, which has some very important useful aspects to it. That said, it's had a really overwhelming influence on the practice of psychiatry. And so because of psychoanalysis and the education about defense mechanisms, such as denial, that's what's taught still. So there's also a lag in our education, where the more recent neuroscience is not being taught as much as the traditional psychoanalytic approach, which is this is denial. The more recent neuroscience says, Well, no, the there's abundant evidence from brain imaging studies, from post mortem studies from neuro psychological assessment studies, that this is a symptom of the brain disorder, just like the delusions or the hallucinations. And people who are in training to become healthcare professionals need to learn about that. So the very, very short answer to your question is, there is a natural lag between science and practice. Second, there is a tradition that we have to break out of, of training people that this is denial. In addition, third, sort of intuitive to think this is denial, and not intuitive. it's counterintuitive to think, Oh, this is a symptom of the brain disorder. And why is that? It's because someone says to me, I'm not sick. So it sounds like an opinion. It's just an opinion the person has, and they have that opinion, and boy, you know, they're clearly seriously mentally ill, so they must be in denial. That statement, I'm not sick and similar statements get tagged as denial, rather than… oh, this is another symptom of their mental illness.

Jennifer Cohen 39:22

Another obstacle is around the issue of stigma. It's commonplace that there's a stigma around mental illness and it certainly can be frightening and disorienting to be around to care for someone with a serious mental illness. I want to ask a slightly different question about it. You discuss in your book, that possibly in an effort to prevent stigma and mistreatment of the seriously mentally ill, there may have been an effort to resist the acceptance that there is a segment of people suffering from schizophrenia who are at increased risk of violent behavior. Can you discuss that?

Xavier Amador 39:56

Sure. The research on this is that if you have anosognosia, and this is in our most recent edition of authoritative diagnostic manual, the DSM. If you have anosognosia, for a psychotic illness, you are more likely to be aggressive. And it kind of makes sense. If I'm surrounded by people who are telling me I'm mentally ill, and I believe with absolute conviction, I'm not mentally ill, I start to get angry. And if my loved ones and healthcare professionals and police officers persist in telling me I'm mentally ill, I might act on that anger. So it's something we really need to pay attention to. And we also at the Henry Amador center on anosognosia, we train police officers, we train first responders, we even train judges and 911 dispatchers on how to de-escalate somebody who has anosognosia, because almost by definition, that person when they're not feeling lonely, and depressed and misunderstood, they're often feeling angry, and oppositional and aggressive, because it feels like – and indeed it's true – the world is against me.

Jennifer Cohen 41:09

And understanding that makes the goal of finding ways to get people to accept treatment, even more of an imperative. So my last question, especially during the pandemic, there's been a lot of attention on the rising rates of mental illness among youth, rising rates of suicidal ideation among adults. Are there reasons to be hopeful about mental health treatment to meet these rising needs?

Xavier Amador 41:32

Absolutely one of the silver linings from the pandemic. You're asking the question because there's a lot of press coverage, media coverage, on the fact that there is a rise in mental illness as a result of the pandemic. So the pandemic has kind of shone a light on the problem of mental illness. It's sad, of course, and not desirable that there are more cases of people really struggling with mental illness as a result of the pandemic. But on the bright side, if you can call it that, it's really lifted public awareness, lifted it up, about the fact that mental illness exists. It's nothing to feel stigmatized about. I mean, I don't feel stigmatized about the arthritis I have in my knee, why should I feel stigmatized by suffering from a serious mental illness? So the pandemic has actually, I think, raised awareness about the presence of these disorders in the imperative that we have this society to help people to help them accept treatment.

Jennifer Cohen 42:39

And if people want to know more about your work, they should go to the Henry Amador Center for anosognosia website, which is hacenter.org. Dr. Amador, thank you for such a fascinating discussion and for your tireless efforts to help so many patients and their families. The world is very lucky to have you.

Xavier Amador 42:59

Well, thank you very much. And thank you for this opportunity.