

# Foreword

by Pete Earley (2nd Edition)

How would you feel Dad, if someone you loved killed himself?

I was rushing my college age son, Mike, to an emergency room when he asked me that question. He was seeing secret messages in bumper stickers and experiencing rapid mood swings. When we reached the hospital, I felt a tremendous sense of relief. *The doctors there would know what to do!*

Four hours later, a doctor finally appeared and after briefly questioning Mike, declared there was nothing he could do to help him. Mike was convinced that he wasn't sick and he refused to take anti-psychotic medication.

Because the doctor did not believe Mike was an "imminent danger" either to himself or others, my son was turned away even though he was clearly delusional.

During the next forty-eight hours, Mike decompensated. Only another parent can really understand how agonizing it is to stand by and watch your child slip further and further into a mental abyss. I tried, of course, to intervene. I told Mike that his anti-psychotic medicine would help him think more clearly. But he told me there wasn't anything wrong with the way he was thinking. I tried to show him that he was having delusions, but he disagreed. Finally, I begged him to take his pills. "Please, please, just do it for me!" But he wouldn't. "I'm not sick," he kept repeating. After hours and hours of exhausting conversations, I demanded that he take his medication or leave the house. That threat only made the situation worse. Afraid of what might happen to him on the street, I backed down. The next morning, when Mike caught me spiking his breakfast cereal with his medicine, he became enraged.

Forty-eight hours later, Mike was in police custody. He had slipped outside one morning and broken into a house to take a bubble bath because he felt dirty. Luckily, the homeowners were out-of-town. It took six officers to subdue him. Mike was charged with two felony crimes.

Uncertain what to do, I contacted the National Alliance on Mental Illness (NAMI), the nation's largest, grassroots mental health organization, and a volunteer there urged me to read Dr. Xavier Amador's book, *I Am Not Sick, I Don't Need Help!*

When I did, I was amazed. Just about everything that I had done to help Mike had been wrong. Rather than calming the situation, my actions had driven a wedge between Mike and me. I had not Listened to him, not Empathized with him, certainly not Agreed with him and finally had not formed a Partnership with him. Those are the four guiding principles behind LEAP, an acronym that Dr. Amador has coined to help teach parents and others how to better communicate with their mentally ill loved ones. When I was arguing with Mike, I had felt frustrated and overwhelmed. In Dr. Amador's book, I found a simple to understand blueprint for parents, siblings, children, and friends to follow. While I was reading Dr. Amador's book, I also realized I was not alone. Others had faced the very same situation that I had encountered with Mike.

I discovered that Dr. Amador's advice came from years of experience as a clinical psychologist. His academic and professional credentials were impressive. He had served as a professor of psychiatry at Columbia University, as director of Research at NAMI, and director of psychology at the New York State Psychiatric Institute. He had worked as an NBC News consultant, appeared on countless television news shows, been quoted regularly in the media, and had been called on by the National Institute of Mental Health, Veteran's Administration, and U.S. Justice Department for advice. Dr. Amador also had served as an expert witness in high-profile cases, including the Theodore Kaczynski "Unabomber," trial, the Elizabeth Smart kidnapping, and the Zacarias Moussaoui "Twentieth Hijacker" case.

But it was another tidbit from Dr. Amador's background that really caught my eye. His brother, Enrique, has schizophrenia. This was important to me, because it meant Dr. Amador not only had professional experience, but also a personal stake in his research. One of the reasons why he had developed LEAP was to help him find ways to better understand his own brother.

Eventually, my son was sentenced to two years of probation and during that period, Mike followed the rules. He attended therapy, participated in group sessions and took his medication. But several months after Mike's court imposed sanctions ended, signs of his illness began to resurface. I was stunned when I discovered that Mike had stopped taking his medication. Despite everything that we had gone through, he had, once again, quit taking his pills. My first impulse was to confront him. *How could you do this again? Haven't you learned any-*

thing? But my wife reminded me of Dr. Amador's book. Using LEAP, she was able to work out an agreement that soon had him back on his medication and into treatment.

In this new edition, Dr. Amador updates his groundbreaking book. He explains how "unawareness" of a mental illness is a *symptom* brought on by the disease. It is *not* a choice that an ill person makes. He gives practical advice about how families and doctors can bridge the gap created by the federal Health Insurance Portability and Accountability Act (HIPAA) that frequently prevents loved ones from being informed and involved in treatment. He summarizes state commitment laws, using simple to understand terms to explain the legal complexities. Since releasing his first book, Dr. Amador has delivered more than more than 300 lectures and conducted hundreds of LEAP workshops. He has taken information from those sessions and added it to this edition. These include model scripts that suggest specific phrases to use and NOT to use. Being able to refer to these passages is much like having Dr. Amador in your hip pocket.

The needs of every individual who has a mental illness are unique. But regardless of that person's specific problems, the basics that Dr. Amador teaches help readers improve their communication skills, help develop trust, and help turn combative situations into cooperative ones.

One night while Dr. Amador was autographing books, a man approached him empty handed. He had left his dog-eared copy at home, he explained, but had stood in line anyway because he wanted to shake the hand of the doctor who had, as he put it, "given me my son back."

I feel the same way.

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# **Preface to the 10th Anniversary Edition**

Xavier Amador (2010)

Why write a tenth anniversary edition? Was it because, like many people, I like round numbers? I remember my tenth birthday like it was yesterday. I was so proud to turn “10” and I suppose I am proud, or more precisely humbled, that *I Am Not Sick* has turned ten years old. This little book, which started out as a labor of love, continues to grow in its reach to family members, doctors, nurses, therapists, law enforcement officers and policy-makers. To my surprise it has been translated into French, Spanish, Hungarian, Chinese and Japanese (more translations are in the works). As much as I do see the appeal of round numbers, their symmetry and the ease with which they can be memorized, I did not revise this book simply because ten years have passed since the publication of the first edition. I wrote it because ten years of experience and new science have been acquired and many more people are asking for even more information on the nature of the problem of poor insight, anosognosia, treatment options and how they can help someone with mental illness who is convinced there is nothing wrong with them.

For owners of previous editions you might, at first glance, think the book is merely one third longer – there are seven new chapters. But as you read you will discover that previous chapters have all been revised. My goal was to update the research and to be even more practical and detailed in the advice I give on how to engage someone with mental illness who does not understand he or she is ill. You will learn several new LEAP tools – I now call the specific communication techniques users of LEAP employ “LEAP tools” (you will see why when you read the first chapter on LEAP). In addition, in this new edition I report on recent research conducted on LEAP, opportunities for training in LEAP

and about new research that points to the importance of insuring persons with schizophrenia, related disorders, and bipolar disorder are involved in treatment and adhering one hundred percent, or as close to that goal as possible, to the medications prescribed. In this new edition I also make the case for why doctors should be assessing insight and diagnosing anosognosia, or poor insight, whenever they assess a patient with schizophrenia, schizoaffective, bipolar or related disorders. Knowing whether the person believes he or she is ill is critical to treatment planning.

It was nearly thirty years ago (in 1981) that I first learned how my natural instinct to confront denial of illness head-on led to disaster. My brother had just come home after his first hospitalization for schizophrenia. The medicine he had been given brought him back to reality I knew, but within a day of his getting home, I found the pills in the garbage can. Naturally, I asked him why he'd thrown them out.

"I'm okay now. I don't need it anymore," he explained.

Since this ran counter to everything he was told in the hospital, I made a point of reminding him. "But the doctor said you're probably going to have to take this medicine for a rest of your life. You *can't* stop taking it!"

"He didn't say that."

"Sure he did! I was at the family meeting, remember?" I countered.

"No. He said I had to take it while I was in the hospital."

"Then why did he give you a supply of medicine to take home?" I argued, trying to prove him wrong.

"That was just in case I got sick again. I'm fine now."

"No. That's not what he said."

"Yes, it is."

"Why are you being so stubborn? You know I'm right!" I said.

"It's my business. Leave me alone."

"When you got sick, it became everyone's business. And besides, I'm worried."

"You don't have to worry about me. I'm fine."

"You're fine now, but you won't be if you don't stay on the medicine."

"That's not what the doctor said!"

"Then let's call him and I'll prove it!"

"I don't want to talk about it! Just leave me alone," he said as he walked away.

With every dose of "reality" I tried to give him, Henry countered with more denials. And with every go-round we both became angrier and angrier.

I thought he was being stubborn and immature. My accusations and threats to prove him wrong made him angry and defensive. My natural instinct to confront his denial was completely ineffective and made things worse. We got caught in a cycle of more confrontation and denials (what I call the *denial dance*), which pushed us farther apart. The end result was always that he walked away angry. And then he would relapse and end up back in the hospital.

In 1989, when I first started doing research on the problem of denial there were fewer than ten studies in the research literature. When the first edition of this book was published, there were more than one hundred. When the 2<sup>nd</sup> edition was published four years ago there were just over two hundred. Today, there are close to three hundred! The avalanche of new research on the nature of the problem and how we can best help persons who say "I'm not sick, I don't need help!" continues. We have learned a great deal which I will tell you about in the pages ahead.

One final note, over the last ten years I have given several hundred talks and workshops on the problem of denial and the solutions offered in this book (i.e., LEAP). LEAP seminars have

been presented all over the United States, in many cities in France, Belgium, Australia, New Zealand, the United Kingdom, Hungary, Portugal, Turkey and Spain.

Because of the demand my colleagues and I started a training and research institute aptly named “LEAP Institute” (see *www.LEAPInstitute.org* for information and free resources). We have learned a lot about what works and what doesn't. Over the past decade I have learned much from our experience with thousands of patients, families and therapists all over the world, and from the new research. These are the reasons, not the number ten, that I felt a new edition was needed. I am very excited about how much more practical and informative this new book is and hope that you will feel the same.

I end here with a quote from my foreword to the first edition: “After my lecture [about the research on poor insight] I was surrounded at the podium for nearly two hours speaking with family members who wanted advice and a greater understanding of why their loved ones refused to accept help. The yearning of these people to learn more and to talk to someone who understood their frustration was enlightening. I was also struck by the realization that the scientific advances with which I was so familiar hadn't yet reached many of the people who would benefit most from what has been learned. That is why I wrote this book.”

This realization, that many clinicians and family members had not yet learned of the research related to this problem, is nearly as true today as it was ten years ago. Tens of thousands are now informed, but given the scope of the problem of poor insight, millions more have not yet benefited from the science you will read about the pages ahead. My hope is that this book will finally close that gap between science and practice.