

“Beyond Madness,” an Interview with Dr. Rachel Pruchno

Summarized by Thomas T. Thomas

Dr. Rachel Pruchno, who holds a PhD in psychology, is an endowed Professor of Medicine at Rowan University in Glassboro, NJ, and Director of Research at the New Jersey Institute for Successful Aging. Her book, [*Beyond Madness: The Pain and Possibilities of Serious Mental Illness*](#), covers wide-ranging topics such as stigma, resistance, resilience, the history of mental illness, obstacles, research findings, legal aspects, and securing financial benefits. Because of the time difference on the East Coast, she spoke on a Tuesday morning with several NAMI East Bay board members in a Zoom meeting that was recorded for all interested parties at our usual “Fourth Wednesday” speaker meeting.

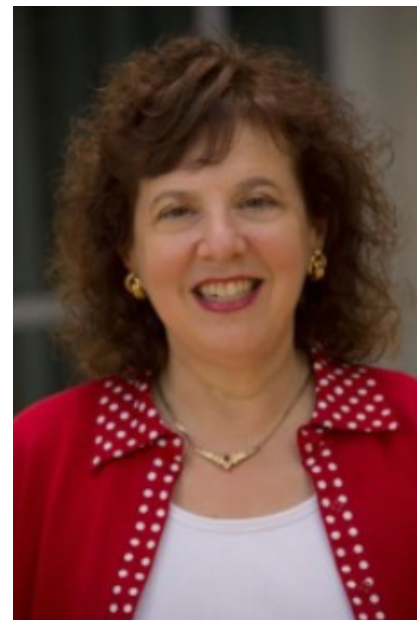
“While there’s a lot we don’t know about serious mental illness,” she said, “there’s a lot that we do. And this information is not getting to the people who need it—families, police, and helpers.” And that is the reason she wrote the book.

Rachel Pruchno’s own mother suffered from manic depression, which we now know as bipolar disorder. The family kept it a secret, as people did in the 1970s. Then she and her husband adopted a daughter who began showing symptoms of mental illness at the age of four or five, and again they didn’t tell anyone about it. When her daughter was eighteen, fell in love with a man in her psychiatric ward, and ran away, Pruchno felt she had to tell someone. She began writing her experiences, and the result was the book [*Surrounded by Madness, A Memoir of Mental Illness and Family Secrets*](#), which she self-published because she could not wait two years to find an agent and traditional publisher.

She wanted to use the book as a platform for public speaking. She addressed college students who were studying to become social workers and psychologists and asked them, “What can we do better?” The result was her current book, *Beyond Madness*. (She is also co-editor, with Michael A. Smyer, of [*Challenges of an Aging Society*](#).)

In *Beyond Madness*, she reports in part on the experiences of “three heroes” with serious mental illness who opened their lives to her, so that readers could understand the realities of real people. And because she is a research psychologist, she includes about thirty pages of reference materials. But she wrote the book to know what to do and how to get help for her daughter. Although her publisher, Johns Hopkins University Press, mainly markets the book to scholars and academics, she intends the book for families.

Q. Your book covers a lot, but I’m interested in your talk about vocabulary. We substitute “mental health” for “mental illness.” And where once we talked about



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“patients,” the proper term became “consumers (of psychiatric services),” then it was “peers,” and now “persons with lived experience.”

A. I think we use “mental health,” because we are trained in human health and creating healthy families. But the book focuses on serious mental illnesses like schizophrenia and bipolar disorder. These are brain disorders, illnesses. Mental health is a continuum on which we all have good days and bad. And mental illness is also a continuum but of another kind. What the heroes in the book teach is that people with serious mental illness can also have physical health, a family, a job, and so on.

We struggle with terms like “madness,” but madness is doing the wrong thing again and again. Institutionalizing people—holding them in a secure place for their own protection—seemed like a good idea once, but over the course of history these places became hellholes.

Q. In the 1960s, a favorite class at U.C. Berkeley was Abnormal Psychology, which focused on nature versus nurture. And they always tended to blame the family, or nurture. People in the field still seem to blame families.

A. Mental illnesses are a combination of nature (genetics) and nurture (environment)—and it’s complicated. There are so many things that can go wrong with the brain in so many ways.

We think culture, the stigma against the mentally ill, has changed, but it hasn’t really, not from the 1960s to the 2000s. You just don’t sense it unless you are touched by mental illness in your own family, or among your neighbors or colleagues. However, young people today do seem to be more accepting of people who are different.

Young people are not afraid of their own differences. They will show up at camp with bags of their medications and say, “Oh look! We’re taking the same ones!” And if college students have a mental breakdown, where before they would have to drop out and go home, today they stay on campus and demand accommodations.

Q. My daughter has borderline personality disorder. This condition seems to fall into the cracks, more of a personality dysfunction than a brain dysfunction. But BPD has been around for a long time, with a history of hysterical and deviant women falling into the category.

A. We certainly need more research on BPD. Unlike schizophrenia and bipolar disorder, there are no medications for it, because we don’t know what causes it.

Cognitive Behavioral Therapy (CBT) seems to work with BPD. But the patient has to work hard with it for CBT to be effective, and some patients don’t want to put in the work. It’s not easy, like giving the person a pill.

Q. Society has gone back and forth between institutionalization and deinstitutionalization. Right now we seem to be swinging back with California’s CARE Court and other programs to push people into services—which are opposed by the disability rights community.

A. This is a hot topic. The mayor of New York City recently called for rounding up the homeless and hauling them off to hospitals. But you can’t force anybody to do anything. The person with mental illness must be part of the solution. They are people first and have rights.

But do they have the right to live on the street? A California judge recently decided that a homeless man who was eating roadkill, dead racoons, was able to find food and so was not “gravely disabled.” Nobody should have to live like that, but we don’t have enough hospital beds for the homeless. The system is messed up.

Q. We also don’t have enough clinicians, service providers. The position of social worker and psychologist is not well paid or respected. And psychiatrists who went into the

field to help people have become psychopharmacologists, handing out pills after a five-minute consultation.

A. If I had my career to do over, Pruchno said, I would become an adolescent psychiatrist. So many serious mental illnesses show up for the first time in the young.

Q. Would this be an opportune time to involve politicians? After Covid isolation and the rash of gun violence, could we get politicians to focus on mental health issues?

A. In reality, politicians would only get seriously interested if their own children got sick.

Q. What about the increasing use of telehealth interviews and applications that help you track and stabilize your moods?

A. Telehealth became popular during the pandemic, when it was the only option. But we found then that it was also cost-effective. We will see more of this in the future, but its effectiveness depends on the competence of the physician using it.

Q. What strategies work with anosognosia, the tendency of a patient to deny that he or she is sick?

A. There is no strategy that works for everyone, and no medication seems to affect it. As a parent, it helps to find the time and place, the right conditions, to have a conversation about it. Of the three heroes in the book, a younger woman with bipolar disorder could understand that there was something wrong with her. But the two men with schizophrenia did not, or at least not until they were much older.

Q. In the book, you talk about “supported decision-making.” Is that similar to a Wellness and Recovery Action Plan (WRAP)?

A. It may be similar. Supported decision-making means having a group or a person who helps you make decisions or can make them for you when you are incapacitated. It’s a step in the right direction to have a plan, catch the person when they are in a good place, and ask what they would want. You can’t work around the person; you have to work with them.

Q. At one point in the book you talk about taking people off their medications and that not being detrimental.

A. The approach works for some people but may not work for others. People’s needs for medication change with age and with conditions like menopause. As they grow older, they may need less medication or different medications.

Q. I remember reading that during the Covid pandemic, people with schizophrenia were four or five times more likely to die than others. Could this have had something to do with their medications?

A. It’s more likely to do with their health being poorer. We know that people with severe mental illness seem to die younger. We just don’t know what causes it.

In general, though, we need to get more services for people with serious mental illness. We are making progress, but so many people and their families are suffering. However, recovery is possible. The three heroes in the book are getting their lives back through care and treatment.