

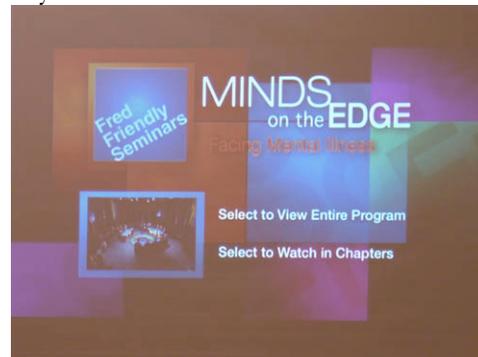
Minds on the Edge: Facing Mental Illness

Summarized by Thomas T. Thomas

At the November 24 meeting, we reshowed a one-hour video that first aired on PBS stations in the fall of 2009 called *Minds on the Edge: Facing Mental Illness*.¹ The video, one of the Fred Friendly Seminars, explores severe mental illness in America as part of a national consensus about how to improve the kinds of support and treatment available for people with mental illness. It explores the challenging ethical issues as well as systemic flaws in program and policy design, service coordination, and resource allocation yet provides a glimpse of innovative solutions being implemented across the country.

Moderated by **Frank Sesno**, Director of Media and Public Affairs at The George Washington University, the video took the form of a roundtable discussion. The panelists represented a wide array of medical, legal, and personal experience, including people with mental illness and those who take care of people with the illness. The panel members included:

- Associate Justice **Stephen Breyer** of the U.S. Supreme Court.
- **Arthur Caplan, PhD**, Emanuel and Robert Hart Professor of Bioethics, Department of Medical Ethics, University of Pennsylvania.
- **Pete Earley**, author of *Crazy: A Father's Search Through America's Mental Health Madness* and former *Washington Post* reporter.
- **Frederick J. Frese III, PhD**, faculty member in psychiatry at Case Western Reserve University and Northwestern Ohio Universities College of Medicine, and a person with schizophrenia.
- **Avel Gordly**, founder of the African-American Mental Health Commission, former member of the Oregon House of Representatives, and mother of a person with schizophrenia.
- **Eric Kandel, MD**, neuroscientist awarded the Nobel Prize in 2000 for his work on the physiology of memory.
- **Judge Steven Leifman**, Miami-Dade County Court Criminal Division, Special Advisor on Criminal Justice for the Supreme Court of Florida.
- **Estelle Richman**, Secretary of Public Welfare, Commonwealth of Pennsylvania.



¹ <http://www.mindsontheedge.org/>

- **Elyn Saks**, Associate Dean at the University of Southern California’s Gould School of Law, a person with schizophrenia and author of *The Center Cannot Hold: My Journey Through Madness*.
- **Thomas Simpatico, MD**, former Director of the Division of Public Psychiatry at the University of Vermont’s School of Medicine, President of the Vermont Psychiatric Association.
- **Tracey Skale, MD**, Chief Medical Officer of the Greater Cincinnati Behavioral Health Services.
- **Lauren Shapiro**, Director of Public Policy, National Coalition of Mental Health Consumer/Survivor Organizations, and a person with schizophrenia.
- **Susan Stefan**, Attorney at the Center for Public Representation, Newton, Massachusetts.
- **Sam Tsemberis**, founder and Executive Director of Pathways to Housing, faculty member at the New York University Langone Medical Center.

During the discussion, Sesno posed the situations of two hypothetical patients. One was a young woman in college who is exhibiting symptoms of bipolar disorder. As her condition deteriorates, her professors and family try to get her into treatment. The other hypothetical patient was an adult male already diagnosed with schizophrenia. When his only remaining parent dies, he loses his source of support and connection to the community, becoming homeless and a danger to himself.

The moderator then asked the panelists to role-play from the points of view of the patients, the student’s parents and professor, doctors in various settings, the police, the judge, and a local politician, all of whom are either trying to help the person or are required to deal with the situation.

As they worked through the attempts of family, friends, and society to help these people on the edge, the panelists made many insightful observations:

- Our mental health system is the definition of insanity—doing the same thing over and over and expecting a different outcome.
- The system is not really a system but “a lot of things put together with bubblegum.”

Arthur Caplan explained that “in our health care system, we love to rescue [people], but we don’t want to prevent [mental illness].”

Dr. Eric Kandel observed that schizophrenia is “an extremely complex brain disorder” and requires medical treatment. He noted that “the incidence of mental illness has not changed in a hundred years,” and yet medical science has made much greater progress in the treatment of purely physical illnesses.

However, as Sam Tsemberis noted, “very few people referred out of an emergency room make it to a [medical] appointment.” The panelists cited the reasons for this: delays of sometimes weeks between the ER visit and the appointment, and the disordered and deteriorating state of a consumer waiting for treatment.

- People outside the mental health system don’t think of mental illness as just another illness. They think there is something unusual about it.

In the current system, Fred Frese said, people with mental illness are being “locked out by chronically normal people who know nothing about mental illness.”

- As to the experience of the illness, Ellen Saks said: “A psychotic episode is like a waking nightmare. Things are disordered, bizarre ... experientially, it’s a feeling of utter terror.”
- What the person with mental illness wants is to be offered opportunities and a chance to be treated as a member of society. In the words of Sam Tsemberis, “We’re talking about creating opportunities for people.” The person with a mental illness, he said, is ultimately looking for “not a disability framework but a *capability* framework.”

Frese suggested that people with mental illness could best be served by being offered some kind of job, perhaps part-time, perhaps minimum wage, but something that would give the person self-respect and dignity.

- Fred Frese spoke emphatically about the place of people with mental illness in society: “We are not going to be called nuts and wackos and psychos anymore. We’re going to be accepted as fellow human beings.” But he also admitted he was glad when people finally made him get help.
- People who work in law enforcement, who are usually the first person outside the family to see the patient during an episode of psychosis, need crisis intervention training.

Pete Earley observed that “in the 1950s and ’60s we had a million people in state mental hospitals. ... Now we have 300,000 people in jail with bipolar syndrome,” as well as comparable numbers for other mental illnesses.

Judge Leifman said, “Judges are more likely to see consumers with mental illness than psychiatrists. ... We have over a million people a year in this country arrested with mental illness.” The judge noted that in Florida a third of the mental health money was going to restore competency so that the people could then be tried and sent to jail.

- During the hearing process to evaluate the person for treatment as “a danger to self or others,” there are usually conflicting purposes. The court and the family want to see the person made safe; the attorney representing the person wants to see his client’s wishes fulfilled. Ultimately, these are different visions of the person’s autonomy.

However, Justice Breyer observed that “when we had a law that made it easy [to commit people], the hospitals were warehouses and people were forgotten.”

- Locking people up—which is the result in the criminal justice system—doesn’t produce treatment.

Estelle Richman said that “we need programs that have case management—someone who takes responsibility for the consumer.” Several of the panelists agree that involuntary assisted outpatient treatment (AOT), such as embodied in Kendra’s Law in New York State and Laura’s Law in California, was a step in this direction.

The closing comment by Dr. Eric Kandel was a hopeful one. Biological science is capable of focusing enormous power, having shown great progress in dealing with other medical conditions. Mental illness presents the greatest challenge that biology has ever faced: understanding the human mind itself and its relation to the physical brain. But he felt sure that eventually biology will show progress here as well. “These are absolutely soluble problems,” he said.