SPEAKER NOTES

A Discussion with the Author of "American Madness"

Summarized by Thomas T. Thomas

At our September 25 informational meeting, **Alice Feller, MD,** discussed her book *American Madness*. With the subtitle "Fighting for Patients in a Broken Mental Health System," her book covers not only serious mental illness and difficulties around diagnosis, but she also shares her personal experiences with clients and the varying contexts in which she has had these experiences. Feller gives the history of legislation and pinpoints the issues which she feels are detrimental to the process of providing good care and support to our ill relatives.

Feller began her study of serious mental illness in high school, when she wrote a term paper on schizophrenia because she and her sister believed their father had the disease—it turned out he didn't. She went to medical school and chose psychiatry. After graduating, she worked in mental health at hospitals, in private practice, and at public clinics in the East Bay.

She began her talk by discussing diagnosis and the difficulty of analyzing symptoms. Families are confronted with a variety of symptoms in their loved one and can't figure them out, often because psychosis is something they don't think about, have no experience with, and hope it is not occurring. But as time goes by, schizophrenia—although it often is masked by other illnesses—will reveal itself.

Borderline personality disorder, Feller pointed out, is not a medical condition and does not respond to medication, although it's difficult to distinguish from schizophrenia. She noted that people with the disorder tend to be "splitters," seeing other people and situations as either all good or all bad.

Stimulants like cocaine and methamphetamines can also cause temporary psychosis. And heavy use of alcohol or cannabis can cause depression. But these conditions are transient.

Feller shared vignettes of four patients from her experience:

- A man with a methamphetamine addiction who was living under a freeway with his girlfriend. He accused Berkeley Mental Health of "stealing his stuff" when they tried to move him into a hotel. Feller noted that long-term relationships, like the girlfriend, are rare in people with psychosis.
- A young man with bipolar disorder who acknowledged his illness. He had speeding thoughts but refused medication because they slowed his thinking.
- A woman who was 5150'ed because she got up on the counter and danced. Her episode of bipolar disorder was apparently triggered by the trauma of discovering her husband at home dead in bed. She was "regrounded" with lithium.
- A boy with schizophrenia who was kicked out of the house, living on the streets and sleeping on buses until his pass ran out. He was taken to John George and responded to medication.

Feller then described the experiences of people with different kinds of severe mental illness.

Bipolar disorder is cyclical. A person can go into a manic phase, with booming self-confidence, and often make bad decisions. They feel good, the life of the party, and unafraid. Then a long-term depression sets in that is hard to treat. Bipolar disorder responds to mood stabilizers like Depakote and the classic treatment, lithium.

With schizophrenia, the person often is not aware of being sick. They may have auditory hallucinations like cruel voices expressing their worst fears. They will feel special, with powers to save the world. They will have unusual thoughts and delusions. They will also feel suspicious and persecuted. They will have disordered communication and find it hard to make themselves understood.

Feller described a schizophrenic patient who lived with his mother and had wonderful kids, who described himself as "95 percent normal and 5 percent hallucinatory," with voices and fears of the most awful things.

Some people with mental illness experience Capgras syndrome, the delusion that a person close to them has been replaced by an alien, a demon, or a doll.

Feller said that early intervention, within months of experiencing the first symptoms, can stop the progression into full-blown psychosis. This requires an intensive treatment program of two or more years, including family involvement, long-term psychotherapy, long-term psychiatric care, and getting the patient back into the world. Family involvement means communicating with the psychiatrist and asking questions. The process is a collaboration among the patient, clinicians, and family. Feller noted that there is one small program with such early intervention in Alameda, and there should be more.

Early signs of a developing psychosis would be if the person were having unusual thoughts and delusional ideas; if they seemed suspicious of others or felt persecuted; if they felt self-important; if they were seeing and hearing things others didn't, like flashes of light or a ringing telephone; and if they had disorganized speech. But sometimes it's difficult to separate these symptoms from drug use—or even just the way normal adolescents can sometimes be.

She then described some of the current problems with treatment in her experience.

The first problem involves analyzing the patient's medical and social history. The practice of keeping electronic medical records means that everything is recorded and sticks. The patient's initial diagnosis as recorded by an intake social worker, usually in the emergency room, remains in the system. That person often puts down a diagnosis of schizophrenia, which becomes locked in. Because medical records are used for billing, and because insurance pays the most for schizophrenia, there's a tendency—called "upcoding"—for the diagnosis to remain unchallenged. This becomes a problem when the patient is treated with the wrong medications for his or her condition.

A second problem is the amount of time a psychiatrist gets with the patient. In a clinic, this can be as little as half an hour a month. Hospital treatment is important because then the patient is then seen every day, and the doctor gets input from nurses and others on the ward. But there are not enough hospital beds.

One reason for the lack of beds is the Medicaid Institutions for Mental Diseases (IMD) exclusion, which prohibits federal funds being spent to treat patients with mental illness or substance abuse at facilities larger than 16 beds.

Another federal law limiting treatment of those with mental illness is the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which provides for patient confidentiality. Too often this is interpreted as not being able to talk to anybody about anything. But while families often can't get details of their loved one's illness, insurance companies are exempt and get the full medical record. So, the patient is discharged from the hospital to the street and the family doesn't know.

Asked what her prescription would be to institute the best practices, Feller suggested:

- Adding to the number of local hospital beds.
- Increasing early intervention programs for psychosis.
- Educating parents, schools, and counselors on signs of developing psychosis.
- Ensuring people getting medical and clinical degrees are given experience in serious mental illness.

Q. Can you do an accurate diagnosis if a person is taking drugs along with their mental illness?

A. You can't do it immediately. But the way the system is set up, there is a pressure to get people into and out of the emergency room quickly.

Q. In terms of substance abuse, do people who get the drugs washed out of their system and are discharged later develop psychosis?

A. If symptoms are caused by a drug like methamphetamine, then they must be treated as a mental illness. But Feller had no experience of meth use causing a long-term mental illness.

Q. Is it important to involve peers, persons living with mental illness, in the recovery process?

A. That can be important in the treatment, but Feller said she had no experience with it.

Q. How do you talk to someone in psychosis when they don't want to talk or are afraid to talk?

A. If someone won't talk, then ask them simple questions, such as what they like to eat. Or talk about something other than the person's illness. Sometimes, too, it helps to just sit and be a good listener. You can get a "gentle feeling" going.

Q. What about the issue of isolation? Do people in board-and-care facilities get support and enhancement?

A. Feller's impression of board-and-cares is that patients are not connecting with people around them. They are often frightened and guarded. The facility operators need more help in this regard.