# Berkeley Mental Health Solicits Input from Consumers and Family Members; Fred Frese Describes Coping Mechanisms for Living with Schizophrenia

*Summarized by Thomas T. Thomas*

At our July 26 meeting, members first heard a presentation from **Kathy Cramer,** Mental Health Program Supervisor, and **Christine Fry,** Intern, from Berkeley Mental Health (BMH). They described some new programs in Berkeley to solicit input from mental health services consumers and family members. Afterward, members viewed a video of **Fred Frese,** a psychologist who also suffers from schizophrenia. He directs a large treatment center for this illness, sits on NAMI[1] National's Board of Directors, and is a favorite speaker at NAMI conferences and workshops across the country. In the video, Frese speaks to a NAMI-sponsored convention in Minnesota for consumers about his experiences as a recovered schizophrenic and the coping mechanisms he has developed for living and working with "chronically normal people."

**Berkeley Mental Health**

As part of the Mental Health Services Act passed by California voters last year, Berkeley Mental Health will be receiving $900,000 in addition to the allocation from Alameda County, Kathy Cramer said. Berkeley is one of two cities in the state with their own mental health departments, and so they get separate funding under the act. One use of the money will be to support a new position called the Family Advocate, and Cramer circulated a draft job description, asking for input from NAMI members. The position is intended to support family members of people with mental illness, provide them with references to available resources, work inside BMH to provide its service teams with information and training on families' issues and concerns, and become a voice for families in Berkeley's Health and Human Services Department. Members who want to discuss and provide input to this position should call Cramer at 510-981-5229.

*CHRISTINE FRY (LEFT) AND KATHY CRAMER*

BMH Intern Christine Fry, who is a masters candidate in public policy at the University of California, Berkeley, described several meetings and commissions that seek input from family members. These include a Town Hall Meeting on Tuesdays at 1 p.m., a new Quality Improvement Committee that is just starting up, and a Wellness/Recovery Task Force. There is also the City of Berkeley Mental

1. NAMI is the National Alliance on Mentally Illness.

Health Commission that advises both BMH and the City Council about mental health issues. The commission currently meets the fourth Wednesday of every month at 6:30 p.m. As this conflicts with the NAMI East Bay meeting, the city may move the meeting date and time. Fry circulated applications to join the commission, which is limited to Berkeley-Albany residents.

The commission also seeks input on its Protocols Committee, which meets the first Friday of each month at 1 p.m. This committee deals with issues such as medication concerns, informed consent, police involvement in 5150s,[2] BMH emergency preparedness for providing services in the event of a disaster, and crisis training for the Berkeley Police Department. Members interested in joining should contact Chairperson Pam Wilson at 510-549-7387.

**Fred Frese on Schizophrenia**

In his presentation to mental health services consumers, Fred Frese described a young man going down the street and stopping at a red light, at every red light he saw, even if he was not at the corner. Then he went into a church and helped the priest say mass and later ended up barking like a dog and writhing on the ground. He was taken to a mental health facility where he awoke, strapped down, not knowing his own name, extremely thirsty, and screaming for water. After a time he was let out of seclusion and he wandered through the facility, not knowing what city he was in, not knowing a single person, but believing the patients had been his friends. He would stand on the staff's desks and lick dirt off the dayroom floor. One day he was asked if he was ready to leave and, knowing that he was still confused and delusional, he said yes. He was then released to the cold streets, where he was alone, had no work, and could do nothing for himself. His family finally found him and put him in a mental hospital where he was diagnosed as schizophrenic. He was told he would gradually get worse and remain ill for the rest of his life.

Frese was, of course, talking about himself as a young man. After ten hospitalizations he actually overcame his illness. In 25 years he earned three degrees in management and psychology and has worked as a psychologist in Ohio's largest state mental hospital. He considers himself recovered, although he still has occasional symptoms and relies on his wife and a few close friends to help him live with the disorder.

*FRED FRESE*

The topic of mental illness and schizophrenia should not be taboo, Frese said. A person needs to know what it is in order to live with a brain that occasionally lapses into psychosis. Frese himself could not say what led to his own recovery, although he mentioned taking medications. Schizophrenia is "a disorder of the belief structure," he said. What he offered, therefore, were a set of coping mechanisms for a person with schizophrenia for dealing with chronically normal people (CNPs).

2. 5150 refers to the section of the California Welfare and Institutions Code that addresses detention of persons who represent a danger to themselves or others.

First, there was the question of what to call himself. Frese rejected "schizophrenic" and the popular "consumer." He preferred "person with high-density D2 [dopamine 2] receptors in his basal ganglia," although he acknowledged that name was too long. This definition is literally the truth. Research into mental illness is showing that there are physical causes for the condition—among them the overabundance of D2 receptors. We can now point out with a high degree of confidence, he said, how the disabled brain differs from other people's brains and causes the person to behave and believe differently from a normal brain. This is similar to having a broken leg, except it's a broken brain. "We have a physical thing that we react to," Frese said. "It's not that we are crazy or bonkers. We have a physiological abnormality."

He said that normality is seductive. After recovery, you want to believe that "it's all over." But the disease is episodic in nature. It is never all over. A psychotic relapse is always possible. If it does not happen, that's because the person has been lucky and has not met up with the conditions that trigger the disorder.

Frese noted that persons with schizophrenia are extremely sensitive to insults, hostility, and criticism. These interactions precipitate and exacerbate the disorder. The brain-disabled person may try to avoid situations where insult and criticism are likely, but this is not always possible. Under abuse the brain freezes and cognitive functions lock up. Frese described a card he carries which reads in part: "I am a person suffering from schizophrenia. When you confront me with criticism and hostility, you make me ill. Please restate your concern in a way that does not disable me. I appreciate your consideration." He has actually used this card on occasion to deflect situations that could cause a relapse.

A paper from the American Psychological Association has noted that recovered psychotic persons may seem "off" in social conversation modes with normal people, Frese said. This is due to a delay in processing internal information. "Our minds are working on so much inside that we put the external world on hold," he said. The normal person, or CNP, looks for visual and verbal cues that tell him the other person is receiving the message as they talk. Persons with schizophrenia don't give this feedback, and it upsets the normals. The recovered person needs to know this and remember to give these cues.

Other elements of skewed social interaction are that recovered people are easily distracted, and they don't make eye contact. Looking directly at another person is distracting, so the person with schizophrenia looks at the wall, off into the air, or over the other person's head in order to focus on the question or topic of discussion. But this looking away makes normals feel uncomfortable.

Recovered people are comfortable with each other and don't need these social cues. They are also able to "jump topic" rapidly with each other—another thing that makes CNPs uncomfortable. "Like Vietnam veterans," Frese said, "other recovered people have been through the same wars you have." Frese noted that people with schizophrenia do not always want to tell the normals about their disability. If a person does decide to be more open with select people, it's usually easier to behave naturally and hope that the normal person will come to accept it.

Another thing that sets people with schizophrenia apart is their logic. Normals follow rational, logical behavior using linear, Aristotelian logic. Recovered

persons use a poetic logic or "paleologic" that has more to do with relationships, metaphors, and a kind of mysticism. Psychologists call this "circumstantiality." The recovered person has a hard time staying "on topic"—hence the tendency to "jump topic" as noted above. For example, if everyone is talking about the World Series, and the Atlanta Braves are in contention, a recovered person asked about the team might focus on the word "brave" and reply about how brave solders in a war must be. Normals are better at sticking to rational logic, while recovered people must guard against being pulled into metaphorical relationships.

This metaphysical logic leads to normals feeling that people with schizophrenia exaggerate. For example, a recovered person might say in passing "I went to Harvard," without mentioning that it was on a day trip, and not a college career, or mention seeing Einstein in class and leaving the impression of being one of his students. This perceived exaggeration can lower a recovered person's credibility.

On the other hand, to guard against this tendency, recovered people often over-explain things. Frese described walking across the hospital grounds with another recovered person and approaching a door he knew to be locked. Rather than just saying it was locked and that they had to go around the building to another door, Frese got into a lengthy explanation of the reasons the door might be locked, who was working on the other side, how long the work would take, and so on. The person he was walking with paused and said, "We do that, don't we?" Similarly, when asked a question, a recovered person might not answer directly but instead talk around the topic, finally coming to the answer somewhere.

If a normal sees a recovered person looking off into space and mumbling, he may think that person is hearing voices and answering them. Actually, the recovered person is most likely rehearsing a reply to a question or an insult that had upset him. Such a situation can be so threatening that the person wants to stop and immediately prepare for the next time it happens. Frese had learned to do this at a more convenient time, such as when he was in the shower or mowing the lawn. One woman he knew did it while driving, when she would turn and pretend to scold a small child invisible in the front seat.

People with mental illness tend to vacillate. A question such as whether to take cream in his coffee will put the person in a quandary and require fifteen minutes to decide and answer. One coping mechanism for when confronted with a restaurant menu—"which has all these choices," Frese said—is to simply have with the person he's dining with is having.

The delusional thinking associated with schizophrenia is episodic, Frese said. The recovered person easily goes from normal thinking to paleo or metaphorical logic and then gets fooled because he thinks, "This is the truth." He needs to learn that when you have this feeling, it's a signal. He also needs to develop confidence in another person—a close friend, family member, or counselor—to tell him when he's doing this. The recovered person can't do it for himself.

People with schizophrenia often feel they are on a "special mission," like Joan of Arc. It makes a person feel he is doing something important and wonderful. Such people are also susceptible to general excitement and, because of

those dopamine receptors, become over-stimulated. Shopping malls with lots of activity, bright lights, and colors can have this effect. At those times, Frese said, he has to go out in the woods, get away. But he is still drawn to activity and excitement.

As to forming relationships with normals and revealing the extent of the disease to them, Frese warned that normals are conditioned to think that people with schizophrenia are violent and dangerous. "So don't throw emotional bombs," he said. It is best to share the nature of the illness slowly, a bit at a time, rather than "pull the mask of every day normality off all at once."

As a final note, Frese said that people in Ohio, working under the Americans with Disabilities Act, have passed measures requiring that jobs in the mental health system be open to people who have recovered from mental illness. "We know all about mental health," he said. "The bureaucrats can learn from us about mental illness."