NAMI EAST BAY NEWSLETTER

A local affiliate of the National Alliance on Mental Illness (NAMI)

January-February 2018

Single Payer Health Care

Wednesday, January 24

Among all the legislative action being taken statewide and nationally, health care is one that perhaps most impacts NAMI families. Specific health insurance plans, treatment options, best practices, medications, etc.—these take up a lot of conversation at support groups and general meetings. Because of this, we are presenting an evening of discussion devoted primarily to the issue of Universal Health Care with members of the group, Healthcare Action Committee. If other legislation appears pertinent to our issues in late January, we'll try to identify the issues of significance. So bring your questions and concerns and join us.

Speaker Meeting starts at 7:30 pm
Albany United Methodist Church
980 Stannage Avenue, Albany
Corner of Stannage and Marin
Meeting is free and open to the public.

Support Meetings

NAMI East Bay offers the following monthly support meetings:

- **Support and Share Group for Families of Adults** is held on the 2nd Wednesday of each month. The next meetings are January 10, February 14, March 14.
- **Support and Share Group for Families of Children, Adolescents, and Young Adults** is held on the 3rd Tuesday of the month: January 16, February 20, March 20.
- **Hearing Voices Group for Family Members** is held the 3rd Thursday of each month at the office, 6:30-8 pm: January 18, February 15, March 15.

Support Group Meetings are held at the Albany United Methodist Church, 7-9 pm. Enter through the gates to the right of the door on Stannage Avenue, turn left through the large room, go down the hall, and come up the stairs. Signs will be posted.

All support meetings are free to NAMI members and non-members, offering a chance to talk with others who understand, give emotional support, and share ways they have found to cope.

Family to Family Class

Contact the office now if you're interested in taking the 12-week family education class starting Thursday evening, January 18. See more about it on our website.

Fundraising and Donations

We know you're waiting anxiously next to your mailboxes, checkbook in hand, waiting for our annual request for donations. Well, take a deep breath and settle down. Due to circumstances beyond our control, we are not sending out a letter this year; in the spirit of celebrating the end of a difficult year, we ask that you put your donation elsewhere—legislative efforts, local and national, would be a good place to start. Postscript: we'll be figuring out how to get a donation process online this year and everyone will be notified regarding it.

That said, we do want to give heartfelt thanks to Sandy Stavi, who donated the proceeds from the sale of her car. That was a truly generous gift and we are highly appreciative of her thoughtfulness.

NAMI Part-Time Position

NAMI East Bay is looking for a part-time office manager. Candidates should have computer skills and will help handle mail, email, phone calls, membership records, office organization, newsletter labeling and distribution, etc. We estimate less than seven hours a week with a competitive hourly stipend. Familiarity with family issues around mental illness is necessary. Contact the office for more information.

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SPEAKER NOTES

Healing Voices: Let's Change the Conversation

Summarized by Thomas T. Thomas

With the harrowing and inspiring stories of individuals who are learning to negotiate and grow through their madness, ***Healing Voices*** challenges us to rethink our cultural understanding of "mental illness" by bringing a message of recovery and charting a course for effective alternative treatments that enable people to live productive and meaningful lives.

This documentary, feature-length movie (available at http://healingvoicesmovie.com) was produced by Digital Eyes Film and written and directed by P.J. Moynihan. One of the film's producers is also one of its participants, Oyrx Cohen.

The story starts with Cohen recalling his first psychotic break, shortly after he enrolled at the University of Massachusetts, Amherst, with all the excitement and stress that the process entailed. He entered an "extreme state of consciousness" and attempted to accelerate his car to the point of taking off and flying away, except that he hit a truck instead. He described his psychosis as "responding to something in the environment that's not right."

The theme that mental illness is as much a response to the conditions of today's society as a sickness in the brain recurs throughout the movie. One in five people in this country in any given year suffer from some form of mental illness. Cohen called these people "canaries in the coal mine," suggesting that they are the sensitive ones who react to our current social problems.

Another of the movie's subjects, Dan, said he had been hearing voices since middle school. Among the many voices, he had an imaginary friend he called "Red Eyes," whom he described as a seven-foot-tall ant demon. Dan said the voices were a gift, but a dangerous gift, and he considered himself "weird in a cool way." But when he went to see a psychiatrist, she told him it was an illness and he should get rid of his symptoms. But Dan saw his voices as allowing him to live.

Jen was a third subject profiled in the movie. She said she is now raising her children in "a consensus reality." As a young woman she had been an athlete, but then she began experiencing mental illness. She tried to be compliant with her medications—she had been on thirteen different drugs—but she felt "foggy." From there, she went cold turkey, "which I don't recommend."

She had been told she had an incurable illness. When she called the help lines in a crisis, they told her she couldn't be helped. Soon after, she found others like herself who "couldn't be helped" and she started a group that met to talk about their situation. "What's labeled mental illness is a mind-body discord that comes out as behavior," she said. "We are not behaving in a constantly narrowing definition of normal."

Oryx Cohen worked with another person with lived experience, Will Hall, to start workshops on withdrawing from medications and founded the Freedom Center, which is modeled on Alcoholics Anonymous. They are not anti-drug, but instead have a welcoming and nonjudgmental approach.

Cohen noted that medication is a spectrum, with on one side the drugs that treat disease, and way over on the other side are recreational drugs like alcohol, nicotine, cocaine, and heroin. But no wall separates the pharmaceutical and recreational drugs, and all of them create an altered mental state. "Alcohol causes brain damage," Cohen said. "But then so do the antipsychotic medications."

Dan said the side effects of his medications were more of a problem than the issue they were supposed to treat. "When emotions are real, they're real. And the negative ones can take you to some dark places."

Marius Romme, the founder of the International Hearing Voices Network, said that as a psychiatrist in Holland he had been trained not to collaborate with his patients. And then one woman resisted the treatment he prescribed for her experience of hearing voices. From that, he reasoned that if this experience is real, then someone will know how to cope with it. And so he turned to the patients themselves.

Peer-run organizations like this have taken off in America. But Cohen noted that, first, you have to overcome the sense that you can't talk about the things happening inside yourself. "People really hear these voices, and they are a part of their lives. Psychiatry says this is a symptom of an illness. But this is an emotional and spiritual reaction to people's problems."

The peer-run organizations don't provide services, Cohen said. They provide a place for people to

come and talk. "People should have a choice in the path to recovery," he said. The peer movement is a social support system teaching that there's another way. It's also based on the civil and human rights movements.

Dan, with the friend Red Eyes, said, "Is it hard to stay in the world? Yeah! When people ask would you do something different, I just wish the voices would schedule their time better."

And Jen said, "The diagnosis—looking at me like I'm in a petri dish—doesn't work. It ignores where I'm coming from and my experience. I'm a human being."

Past articles in the Speaker Notes series are available online at www.thomastthomas.com under "NAMI East Bay." Also available is a copy of the brochure "Medications for Mental Illness."

Note: *After publication of September's* Speaker Notes, *the speaker and the Kaiser organization requested a revision to more accurately reflect the content of their program and its courses. Attached is the revised text.*

Cognitive Behavior Therapy for Psychosis

At our September 27 speaker meeting, **Michelle Sallee, PsyD,** a licensed clinical psychologist with the Department of Psychiatry at Kaiser Permanente, told us about her work to develop and run programs on Cognitive Behavior Therapy for Psychosis. Dr. Sallee also has worked as a forensic correctional psychologist. She came to our attention last spring when her clinical colleagues at Kaiser nominated her for a Mental Health Achievement Award, given by the Mental Health Association of Alameda County.

Her work on cognitive behavior therapy (CBT) for psychosis began with a book by Aaron T. Beck. Dr. Sallee also cited two research studies supporting this form of treatment. One, from 2016, followed 58 students over 45 CBT sessions to examine "dosing"—or the amount of CBT skills training classes needed before it is significantly helpful with psychotic symptoms (see *The Journal of the Association of European Psychiatrists,* October 2016). Focusing on results after five, fifteen, twenty-five, and forty-five weeks of sessions, the study found the students reported reduction in the stresses associated with their psychotic symptoms after 15 weeks, but that 25 sessions are the more appropriate dose of CBTp, as that is when the frequency of positive symptoms of psychosis and negative symptoms of psychosis reached a minimum.

A second study, from 2011, examined the functional effectiveness of CBT versus treatment as usual (TAU) with brain scans by magnetic resonance imaging and showed positive results.

Dr. Sallee developed a 13-week program, Cognitive Behavior Therapy for Psychosis, in December 2012, which undergoes updating and modification at the end of every 13-week skills-based training group therapy program. The program includes a teaching manual and workbook authored by her and Dr. Jessica Bergstrom, who was the Doctoral Practicum student at the time. The course is used by patients with a range of diagnoses, including Schizophrenia, Schizo-Affective Disorder, Major Depressive Disorder with Psychotic Features, and Substance Use Disorder. Some of the patients are on medication, while others are not. The goal is to give them the tools and skills to deal with and reduce the stresses resulting from symptoms such as hallucinations like hearing voices and delusions—although she avoids that word, her patients preferring "thoughts and beliefs that cause stress."

After each course, Dr. Sallee examines with class members what has worked for them and what didn't, and she has made changes. She is now teaching her sixteenth such course at Kaiser. Her work has been so successful that the Kaiser organization in Northern California considers it a best practice and has asked her to train seventy other clinicians around the system to give the course.

CBT was originally used for depression, then for anxiety, and now psychosis. It works from two models. The **circular model,** followed by Dr. Beck, traces the relationship among thoughts that lead to moods, which lead to behaviors, which create more thoughts. The goal of this model is to notice the cycle and break it. "You can't break the cycle at the *mood component* of the circular model," she said, "but you can come into the cycle at *thought,* separating yourself from your belief, examining it, and asking yourself if your thought is a fact or a belief. You can also interrupt at *behavior,* by changing a behavior such as going outside for a walk." That was one idea from a two-page handout listing other adaptive behaviors.

The other is the **ABC model,** which stands for *action, belief,* and emotional *consequences*. "Something happens and you feel a certain way," she said. "It's not because of the action but your belief about it that makes you feel this way." The model suggests the patient put feelings and thoughts in their right place. To this ABC model, "D" is for *distortion,* and her course focuses on 13 distortions that people with psychosis engage in (e.g., jumping to conclusions, fortune telling, mind reading, and other thinking styles that get us all into trouble), which color perception and interpretation of what was seen or heard.

As an example of how CBT works in the course, Dr. Sallee addressed the issue of hearing voices. Often it's not the content but the patient's relationship with the voice that causes stress. She identified three domains into which this relationship can fall: ***malevolent,*** in which the voices wish the patient ill will; ***omnipotent,*** with the voices "knowing all"; and ***benevolent,*** where the voices intend good things. For patients whose symptoms do not include hearing voices, then the relationship can be with the "voice in your head" representing your thoughts that cause distress. In all these domains, the therapy is to separate self from the thought or belief and test to see whether they want to stay with that belief or consider an alternative belief.

The goal of the training is to move the patient's score on the BAVQ-R (Belief About Voices Questionnaire–Revised), which is an instrument developed by the *British Journal of Psychiatry* (2000) designed to measure how patients interact with their A/H. The omnipotent domain can be stressful because it represents an invasion of the patient's privacy. Dr. Sal-

lee and Dr. Celia Yu-Hsuan Liu, who was the Doctoral Practicum Student at the time, looked at pre- and post-test scores, with their pilot group showing movement from a score of eight to a five. For the benevolent domain, the goal would be for the score to remain the same or increase. In their review, the score stayed the same. For the malevolent domain, the goal would be to decrease the score. Their pre-and post-testing with the pilot group showed movement from a score of five to a score of one.

Dr. Sallee teaches four "disputing strategies" for "beliefs that cause distress" (or delusional thoughts) to help patients argue with their thoughts. The first is a strategy called "***Evidence,***" (the "E" column in the ABCD model). Here the patient acts as a lawyer arguing against a belief, such as asking someone with paranoia what evidence there might be that Robert De Niro is *not* actually following him or her. Next is ***cost/benefit analysis,*** in which the patient weighs the pros and cons of a belief. If a patient believes the FBI is watching, the benefit is he or she feels important, but the cost is negative feelings of paranoia and isolation. Third is the ***survey method,*** where the patient asks seven people he or she respects, trusts, and with whom the patient willing to share the stressful belief. (If the patient is unwilling to share, then he or she is asked to internalize what those people would say.)

And if those three strategies don't work, the patient can always ***act as if it's true,*** and what is he or she going to do about it? For example, with a patient who feared an imminent earthquake that would destroy just his own home, the treatment was to prepare an earthquake kit and to learn photography in order to document the results. This positive activity kept the person busy and less stressed.

In addition to these various strategies, the course discusses topics like:

- Auditory hallucinations, their triggers, and coping strategies for breaking their cycle.
- Negative symptoms of psychosis—things that were there before but are now absent, such as expression of emotion, self-care and hygiene, and goal-directed activities—along with their triggers and interventions.
- Commanding voices and the Opposite Action model. For example, if a voice commands violation of an apartment building rule, patients identify the opposite action (opposite of the command) and develop a list of pros and cons to that opposite action. This strategy results in consideration of potential consequences, decreases impulsivity (of obeying a command) due to the time it takes to do this four-step strategy, and they are encouraged to call someone they trust to help with this strategy, which adds the benefit of checking in with someone else about a behavior that could lead to negative consequences (e.g., eviction, police department involvement, etc.).
- Things that worsen psychosis and depression, such as isolation, sleep deprivation, alcohol and drug use, and stresses from emotional conflict and high emotional expression and drama in the household.
- Safety planning, including intermediate steps a patient can take before a break, call to 911, and hospitalization, and triggers that lead such a break.
- A one-hour class facilitated by Kaiser's Assistant Chief of Intensive Services, John Huh, MD, focused on information about medication, behaviors and choices that interfere with how effective medication can be, management of side effects, and patients are encouraged to ask questions (verbally but also anonymously on paper submitted in advance) to help them make informed decisions about medications vs. choices based on fear and lack of education about how medications work.
- Symptoms that are *not* helped by CBT, such as disorganized behavior and visual hallucinations, were added to the program by Dr. Anastasia Finch, who was the Doctoral Practicum Student at the time, when participants requesting learning what *does* work.

The program includes homework for the participants. For example, they are each given a seven-page list of pleasurable and nearly free activities to break the behavioral feedback cycle and asked to try one.

The CBT program is not for everyone, but patients are encouraged to try these strategies and decide for themselves. All participants are seen by Dr. Sallee for a 45-minute office session prior to joining the program. If they are clinically not a match for a group setting, there is a discussion about how the interested participant can learn the strategies. If they are a match for a group setting, the focus of the office setting is "joining" the program in progress (so that patients do not need to wait 13 weeks for the next series to begin, they can start the next week if they choose).

If CBT is not a good fit for the patient's clinical needs or interest, they consider the 12-week Affect Regulation for Moods Associated with Psychotic and Bipolar Spectrum Disorders Program. This uses DBT, ACT, psychoeducation, mindfulness practices, and the recently added class, The Impact of Nutrition on Moods Associated with Psychosis and Bipolar Spectrum Disorders, developed by Angie Gereis, MA strategies. The 12-week program was developed by Dr. Sallee and Dr. Sara Dodd, who was the Doctoral Practicum Student at that time. These programs are limited to Kaiser Permanente members. The course includes skills and tools for managing, regulating, tolerating, and decreasing paranoia, suspiciousness, fear and anxiety, anger, depression and guilt, and hypomanic irritability.

CBT does not work for all psychotic symptoms. For example, while it addresses auditory hallucinations like voices, it has no effect on visual hallucinations. This may be because the therapy is language oriented and these symptoms are not verbal.

The results from CBT for Psychosis have had some variation—statistical outliers—and the treatment does not work for every patient. For example, a patient who thinks too deeply, and becomes stressed by thinking about his or her thinking, may not have a positive response. Dr. Sallee measured the overall success of the program by looking at hospitalization rates before and after the program, then at six, twelve, and eighteen months after finishing. On this basis, the results have been consistently positive.

Other intervention programs at Kaiser in Oakland include the six-week Family Education Support Group for families and friends of patients with mental illness; the Wellness Club (combining skills training, support, and art therapy); the Wellness Graduates Group (a support process group for patients

with psychotic and bipolar spectrum illness), Life Skills Group (focused on patients primarily with negative symptoms of psychosis and chronic illness), the 12-week Bipolar Education Group (psychoeducation and support), and the Bipolar Support Group.

Currently, Dr. Sallee, Dr. Myron Hayes, PhD, ABPP, and Michelle Renwick, currently Oakland Kaiser CCM's Doctoral Practicum Student, are working towards proposing to present both the CBT for Psychosis program and the 12-week Affect Reg Program at the 126th Annual American Psychological Association Convention (August 2018).

For patients outside the Kaiser system, Dr. Sallee suggested they or their loved ones consult PsychologyToday.com to find therapists with special training in CBT and psychotic spectrum and Bipolar spectrum diagnoses. Parents can also help their loved one by undertaking CBT themselves and modeling it for their loved ones.

Musings from the President

This edition's Musings column has been turned over to Katy Polony, a NAMI member who writes so poignantly and authentically about witnessing mental illness in her family member.

"I'm a mom with a grown son with schizophrenia and I'm ticked off. Imagine that! Not with my son, although unpredictable mood swings are not pleasant to deal with any more than the look of torment almost permanently etched on his face. No, I'm annoyed that so much of the time the public presentation of schizophrenia is through the voices of the lucky (relatively) and the very few. I am tired of the Ted Talks that imply that the intolerable pain (this is not hyperbole—a so many kill themselves) can be muscled through to come out the other end with satisfying, even brilliant careers. Some have credited their mother's support for their recovery, thus presenting the rest of us moms with a near impossible act to follow. While I do not doubt the veracity of these stories, they represent a mere sliver of those with this illness.

I would wish that it was my son writing this, not myself. If biology exhibited a moral compass, I would say this illness was evil. It not only supplants rational thought with irrational terror, it deprives the sufferer of the means for escape. Most of those with schizophrenia lose their footing in reality and slip through our grasp into a hell we cannot pull them out of. The illness denies its own existence, thereby sheltering itself, hiding safely in the brains of our loved ones. This is called anosognosia, or, as my son put it while hospitalized at John George, "a Catch-22 where I'm told I'm so ill I don't know that I'm ill." In the two years since that acknowledgement, he has virtually ceased to speak at all about what he's going through. In isolation he clutches to his chest his pain as the illness plucks from him his old pleasures in life, one by one—a bike ride to Lake Merritt to smoke a cigar, a solitary trip to our cabin in the foothills, volunteering to make phone calls or canvass for Bernie, breakfast in the city with family, playing the piano and even reading. What will he be left with? Will it ever be done? I feel it as an alien creature slowly feeding on him from the inside out while I am helpless to do anything but cook healthy food and bear witness to the carnage.

So please, could we have a Ted Talk with a little more of the reality for most sufferers of schizophrenia? Sure. Only problem is, who'd do the speaking?

—Katy Polony, Family Advocate

Supplemental Income Explained

There has frequently been confusion voiced by families about Social Security Retirement (SSR), Supplemental Security Income SSI (SSI), and Social Security Disability Insurance (SSDI). SSR are retirement benefits for those who paid into Social Security from an individual's earnings in most professions.

SSI are need-based funds intended for those who are disabled from working due to physical and or mental disabilities, became disabled after working or never worked, and have little or no income. SSI recipients receive MediCal (Medicaid) with SSI. There are income rules for SSI recipients, such as they can have no more than $2,000 in resources, with exceptions such as owning the home they live in and the car they use.

To be eligible for SSDI, a disabled individual needs to have worked five out of the last ten years at the time they apply for benefits. To be deemed disabled for a mental disability, there needs to be mental health treatment documentation from an MD, PsyD, or PhD. The SSDI recipient will receive Medicare two years after the disability onset date. Generally, our folks receive combined funds from SSI and SSDI. In 2017, the SSI amount for someone who lives independently in California is $895.72 and for couples $1,510.14. The Federal Benefit Rate is $735 per individual and $1,103 per couple.

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We urge you to mail your 2018 dues now. And if you can afford to add a bit more, please do so. Your $40 NAMI East Bay membership gives you our newsletter six times a year, the quarterly "Connection" from NAMI-California, and the NAMI-National "Advocate." NAMI East Bay is nonprofit [501(c)3] and your dues and contributions are tax deductible.

☐ **Family Membership, $60 per year** ☐ **Open Door Membership, $5 per year**

Make checks payable to "NAMI EAST BAY" and mail to NAMI East Bay, 980 Stannage Avenue, Albany, California 94706

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