
NAMI EAST BAY NEWSLETTER

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

July-August 2022

Prevention and Early Intervention in Psychosis: A Window of Opportunity to Change the Course of Serious Mental Illness Wednesday, July 27, 7:30 pm

According to the National Institutes of Health, 100,000 youth and young adults in the U.S. experience a first episode of psychosis each year (NIH, 2013). And yet, it takes 21 months on average before someone can receive specialized treatment for early psychosis after they first begin experiencing symptoms (NIMH, 2019). Coordinated specialty care for early psychosis is a treatment model provided with evidence-based components designed for early detection, individual psychotherapy, strength-based care management, supported employment and education, judicious medication management, and peer and family support.

Adriana Furuzawa, LMFT, is the director of Felton Institute's Early Psychosis Division and oversees the implementation of the (re)MIND[®] programs (formerly PREP – Prevention and Recovery in Early Psychosis) in five counties in the San Francisco Bay Area and Central Coast. Felton's (re)MIND[®] programs were first implemented in 2007 and are nationally recognized for bridging the gap between science and community-based services. Furuzawa will discuss what is psychosis and why it is important to intervene early, with the right resources, to prevent lifelong challenges and to support individuals and families to reach their life goals and dreams.

Speaker Meeting starts at 7:30 pm

The presentation will be **Zoom/online**, and attendees should preregister at our website: <https://namiastbay.org>, click on "What's New," and follow the link.

Note: The meeting will be available in written summary in the newsletter, and video-recorded and accessible via the What's New link on our website.

Support Meetings

For the duration of shelter-in-place and social-distancing orders from Alameda County, NAMI East Bay is offering online **Family Support Meetings** every Tuesday from 6 to 8 pm via Zoom. You can go to our website <https://namiastbay.org>, click on "What We Offer," and follow the link to "Online Support Groups."

Note: Invites to a Zoom meeting will include phone numbers, links, meeting identification, and passwords. You can join any meeting by phone and voice only, but to participate by video you need to download the [Zoom app](#) before joining the group.

CARE Court Moves Through the Legislature

Governor Newsom's CARE Court bill, SB 1338, passed the State Senate unanimously May 25 and is going to the Assembly Judiciary Committee (scheduled for June 21) and the Assembly Health Committee on its way to a vote by the Assembly.

CARE Court introduces a new court system for dealing with serious mental illness, in addition to Behavioral Health Court and Assisted Outpatient Treatment, and in addition to the court system for conservatorship. CARE Court is not conservatorship, because all the services it offers are voluntary. It is aimed at people with schizophrenia-spectrum or other psychotic disorders and offers them treatment and support planned by a court. (The best possible discussion of this nuanced bill is by Sigrid Bathen in [Capitol Weekly, May 18, 2022](#).)

Some peer organizations oppose CARE Court because they claim it forces treatment. Actually, it does not. Some family members were initially lukewarm about it because it doesn't force treatment. Now both groups are hot with passion; some with the fear that it might lead, a year or more out, to treatment if a person is found eligible for conservatorship after CARE

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SPEAKER NOTES

Let's Discuss Meds

Summarized by Thomas T. Thomas

It has been a while since we had a speaker on medications for mental illness. At our May 25 meeting, we heard from **Jeffrey Johns, MD**, who is the Medical Director of the [City of Berkeley Mental Health](#). We asked him to give an overview of the medication issue and how it permeates compliance with interventions and recovery.

Dr. Johns has been with Berkeley Mental Health (BMH) since 2008. He supervises a staff of two psychiatrists, four nurses, and administrators. He noted that five years ago, BMH left its Adult Clinic at Martin Luther King, Jr. Way and Derby Street, but it is now back at that site after renovations. He also said that Steven Golnic-McClurg, BMH's Manager of Mental Health, had stepped down and they were looking for a replacement. Overall, with the Covid pandemic, staffing is a challenge: nurses, social workers, marriage and family therapists, and administrative staff are in short supply.

BMH recently instituted a homeless full-service team. They currently serve 35 patients and hope to expand that to 40 or 50. The city also has a specialized care unit for people in crisis who can be served without resort to the police. And finally, they have expanded coordination with primary medical care, instituting a database, the Community Health Record, that gives BMH staff access to emergency rooms, hospitals, and primary care for their patients.

"People with severe mental illness die about twenty-five years before the average American," Dr. Johns said, attributing this to a lack of primary care. He also noted that these patients are more at risk for Covid, and that people with schizophrenia are four times more likely to die from the disease.

He also said that the state of psychiatry has not changed much in recent years, compared to advances in infectious diseases like Covid and Hepatitis C. The biggest change he noted was in substance abuse, with the increased potency of available street drugs like heroin and methamphetamine.

At BMH, they tend to treat patients with severe mental illness with the "tried and true" medications, like risperidone, olanzapine, and haloperidol. One of

the innovations in this area is the introduction of long-acting injectable antipsychotics. These can be given in three- and six-month doses, so that the patient only needs to take medication twice a year, and this helps with compliance. Patients on these medications no longer have to make the decision to take their meds every day.

Finally, after the doctor's introductory remarks, before taking questions, he thanked NAMI East Bay for its advocacy. And he thanked families for their individual advocacy for their loved ones.

Q. We recently had a letter from a woman whose relative nearly died at Santa Rita jail because his meds were not being monitored. Does the jail have psychiatrists?

A. Santa Rita has good psychiatrists with a standard of care that they try to live up to. But there is a shortage of psychiatrists. And when the psychiatrists want to see a patient, they depend on the deputies to bring the patient to them. So yes, there is probably not enough medication monitoring.

Q. When you see a new patient, what decisions go into medication prescribing? Do you consider family history?

A. Ideally, yes. We talk to family members and look into the patient's records. It can be hard to get enough information from an initial two-hour interview. An in-depth evaluation happens over time, rather than just in the first interview.

Q. NAMI family members have things to share, such as how meds are working with our ill relative. But do you always need the patient to sign the HIPAA (Health Insurance Portability and Accountability Act) release to give feedback?

A. Yes, and it's frustrating for the doctor. We can always listen to the family's concerns but maybe not answer back. However, we can give generic information and non-medical advice. We can get a patient's permission for generalized information to be shared. Most patients will sign a release, but not all.

Q. What is your opinion of the newer medication for adolescents and young adults known as Latuda? My son has an overlapping diagnosis between bipolar disorder and attention deficit hyperactivity disorder.

A. Latuda (generic: lurasidone HCl) may not be as good for schizophrenia and bipolar 1 as risperidone, but it can help. If a person can tolerate Latuda and

respond, he may want to stay with it.

Q. Can a person have a psychotic break after an accident, like falling off his bicycle, or after an operation, like for appendicitis?

A. I don't know about that. We would want to do a psychiatric evaluation in any case. The cause might be a brain injury or medication side effect.

Q. How do you decide which patient needs these long-acting injectables? And are they all done with the needle, rather than pills?

A. The long-acting meds are all injectable. Taking them is always voluntary. The criteria for prescribing them are, first, safety, has the patient had any bad reaction to the pill form? Second, efficacy, is the patient responding well to the pills? And finally, is the patient having trouble taking the pill form regularly?

Q. You talk about "severe mental illness" or "serious mental illness." Are there levels to mental illness?

A. There are various definitions of "severe." Some diagnoses like schizophrenia, schizo-affective disorder, bipolar 1, and PTSD (post-traumatic stress disorder) are considered severe. The county mental health systems in California consider the level of impairment: does the illness interfere with the patient's ability to hold a job, have a relationship, or achieve some other goal? If not, then the illness may not be severe. The definition is how the patient acts on it.

Q. What are the medications for treating hallucinations and delusions?

A. Medications are better at treating hallucinations, which involve sensory impairments, than delusions, which are more complex neural situations.

For hallucinations, Zyprexa (generic: olanzapine), Risperdal (generic: risperidone), Haldol (generic: haloperidol), or Clozaril (generic: clozapine) are commonly prescribed. Clozapine is sometimes the most effective, but it can be toxic and needs to be monitored. But you can seldom remove *all* hallucinations.

Dealing with delusions—which are really the patient's cognitive ideas about how the world works—is tougher, although they are sometimes linked to hallucinations. Then you have to talk to the patient, try to understand his or her thinking, and make room for discussion and a different idea: "Is this the *only* way the world works?" Each patient is different, and some are aware of their delusions while others are not. Some can have delusions and still function.

Q. How do you get diagnosed in the first place?

A. If you have private insurance, you can see a psychiatrist through them. People who come to BMH must live in Berkeley and most are provided with insurance through MediCal, California's implementation of Medicaid. A psychiatrist bases the diagnosis on observation and assessment, and collects the developmental and family history, medical and substance abuse history, before prescribing treatment.

Q. If a person has had only one psychotic break, gets on medication, then has no psychosis, do they stay on the meds forever?

A. Good question—and a controversial one. For schizophrenia, it's generally recommended to stay on medication. With other diagnoses, you can sometimes consider lowering the dosage. But there are not many studies in this area.

Q. My son is having weight gain as a side effect, and this leads to depression. Do the new meds have less side effects?

A. Weight gain is not inevitable. Sometimes you can talk to the patient about diet and exercise. The newer medications like Latuda and Abilify (generic: aripiprazole) are not as strong but have less weight gain. In medications for mental illness, there have been no recent, revolutionary discoveries, nothing really new is coming forward. The research funding—from the federal government and pharmaceutical industry—is now focused more on infectious diseases.

Q. My son has bipolar disorder with severe anxiety, but the psychiatrist does not want to treat him with antidepressants.

A. Antidepressants can trigger a manic episode. You can try a mood stabilizer like Depakote (generic: sodium valproate) or Lamictal (generic: lamotrigine).

Q. How do you treat someone who refuses medication because they don't think they're sick?

A. Then you have to focus on what they want. Do they want better sleep? Less anxiety? Taking their prescribed medication can help with that. And family feedback, showing them how meds have helped in the past, also works.

The full presentation recording is available on the [NAMI East Bay](http://www.nami.org/eastbay) website under What's New. Past Speaker Notes articles are available online at www.thomasthomas.com/NAMI.htm.

Musings

I never know what is going to provoke the content of this regular unsolicited sharing of my musings. This time it was a TV political reporter who said to his hesitant and reluctant interviewee after asking a provocative question and not getting a quick response: “Put words to it.”

We live in a language-dominated world and the exact words we use inform the meaning and context of our communications with each other. Throw in some cultural awareness, political correctness, and body language, and the way we communicate becomes a potential landmine.

Consider, for example, the words used to identify an individual with a diagnosed mental illness. Years ago, the word “patient” was common. Then it became “consumer,” as in “consumer of mental health services.” That transitioned within the last decade to the words “peer” and “client.” Now the word of choice to describe that individual is “person with lived experience.” Since we family members have been drawn into and sharing that experience, we are now also considered “persons with lived experience” for certain behavioral health jobs and services.

This change process is of course not limited to the field of mental health. “Salesclerks” become “sales representatives,” “barbers” or “hair cutters” become “hairstylists,” “truck drivers” are “transport managers,” etc. The vocabulary issue is particularly pronounced when we deal with the gender spectrum. A “he” or a “she” becomes a “they,” and the binary perspective on looking at the world goes topsy-turvy.

The words we use daily inform the world of our perceptions. Psychiatrists have spent many years in training and working inside the DSM (Diagnostic and Statistical Manual), the diagnostician’s Bible. Diagnoses are crucial for appropriate medication or therapeutic intervention, as well as for billing Medical. Having a diagnostic label helps mental health providers get an understanding of a client’s presenting issues, and perhaps a clue to prognosis, but let’s leave the big words to them.

I propose that families soften their vocabulary. For example, doesn’t “thought disorder” sound more benign than “schizophrenia”? Or “mood disorder,” compared to “bipolar disorder”? I think that communication between a consumer and family member is

gentler if the words “shaky” and “up and down feelings” are used instead of “agitation” and “emotional dysregulation.” It’s OK not to sound clinical if that is only communicating stress and pathology.

Obviously, at times it is necessary to not talk around a diagnosis, and that’s one of the communication skills families have to incorporate. A book that we recommended frequently is Xavier Amador’s [*I Am Not Sick, I Don’t Need Help*](#), since it gives concrete suggestions regarding effective communication with our loved ones.

—Liz Rebensdorf, President, NAMI East Bay

CARE Court (Continued)

Court, and some with that same hope clutched to their breasts.

Actually, CARE Court does not include forced medication or conservatorship beyond what the current system offers. It does not change the law about medication or conservatorship. Under the current system, counties can already begin conservatorship proceedings against someone who meets the current requirements for conservatorship (danger to self or others, and/or grave disability).

Even though CARE cannot force hospitalization or medication, families decided CARE Court has some aspects that offer hope:

1. It allows family members to petition for help for their loved ones.
2. It is mandatory for all counties; they cannot pass their responsibility to others.
3. It forces counties to take official note of those suffering in plain sight from serious mental illness.
4. It is focused on people with psychosis who are in danger, not on all homeless people and not on all with mental health issues.

If a person demonstrates during the 12 months of CARE Court that they are a danger to self or others, or gravely disabled, they should be conserved like anyone else. If a person with psychosis is blind and keeps getting hit by cars, is gang-raped on multiple occasions, has untreated diabetes, has their cane and walker constantly stolen, is covered with sores because they cannot clean urine and feces off themselves, or thinks injecting meth is a medically recognized remedy for mental illness, they should have a

chance to be conserved.

Supporters of CARE Court include NAMI California and Families Advocating for the Seriously Mentally Ill (FASMI). Groups opposed include Disability Rights California, the Northern California ACLU, Human Rights Watch, Mental Health America California, and the local Anti-Police Terror Project. Disability Rights California, a nonprofit that gets a lot of state and federal money to defend the rights of the disabled, has boxed itself into the position that no mentally ill person should receive treatment they don't want. This position is impossible to support for people who really know serious mental illness.

Some opposition is based on suspicion of Newsom, of big-city mayors, and of real estate developers; some think that CARE Court is a plot to get all the homeless off the street into camps or compounds. But CARE Court is not aimed at most homeless people; it is not appropriate for them. Most homeless people are not seriously mentally ill, and most people with mental illness function much better than our family members. CARE Court is aimed at 7,500 to 12,000 people with psychosis whose illnesses resemble those of our family members, as opposed to the 160,000 or so homeless in California.

I conclude that our family members will continue to be pawns in this struggle between political forces. Aren't they always pawns? The definition of powerlessness in a bureaucratic state is the inability to lobby for yourself. I suggest you support CARE Court by writing to your state Assemblyperson.

—*Alison Monroe, FASMI*

CARE Court FAQs: https://www.chhs.ca.gov/wp-content/uploads/2022/03/CARECourt_FAQ.pdf

My Ninth Year of Fighting

It's been more than eight years since my family member had their psychotic break and began rotating among homelessness, John George, other psychiatric emergency rooms, Villa Fairmont, Gladman, good board-and-cares, indifferent board-and-cares, jails, and emergency rooms around Northern California. I decided in the first year of this fight that it was not in her best interests to discharge her over and over again to places where she could take meth and be homeless. Whatever the system decided or said, I

would always demand that her health and life be saved. I've done so ever since, through every kind of official opposition.

I was advised early on by a knowledgeable person that it seems that if you fight for your family member in the system, you can extend their life. I have fought and fought and won, eventually, again and again. Then again, even if you fight, any little thing can lead to your family member's demise. Any little thing that can go wrong will go wrong; I've seen it with my friends. Their son missed his medication because of a change in a contractor's appointment procedures; he attacked her and tried to kill her and went to jail. Another son quit taking his medication, threatened to kill his mom, was hospitalized, and fought again and again in court to be discharged untreated. When he moved to another facility, he missed his medication for a week because the facility just ran out (blaming the supply chain). Another outpatient facility delayed his medication claiming he missed an appointment. If you know schizophrenia, and you know this med, you know how dangerous and pointless it is to separate people from their meds. It's just asking for trouble, more trouble.

I feel like I am running out of hate; I know that people in this idiotic system are just doing their jobs, and the system, not the people in it, is to blame for the early deaths of our loved ones. But I am also running out of hope. I do know that she is being discharged from a hospital once again to a situation though well-intentioned is unsafe. Perhaps unfortunately, I know now that these feeble, ridiculously optimistic measures are the best the system is willing to offer, because it still believes everyone must be given a chance, regularly, to choose early death on the street. Many in the system still claim to believe that involuntary treatment or hospitalization is wrong. I just have to speak up. More and more, it feels like yelling into the wind, because I know how sketchy, inadequate, reckless, and mendacious the system is—taken as a whole. But there's a chance the paradigm is changing, and that with the help of Governor Newsom and others, there can be a new consensus that we need to take responsibility for people with brain illnesses that keep them from making lifesaving decisions themselves.

—*Alison Monroe, FASMI*



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We urge you to mail your 2022 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

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