NAMI EAST BAY NEWSLETTER

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

May-June 2022

Let's Discuss Meds

Wednesday, May 25, 7:30 pm

We are delighted to have not one but two psychiatrists from Berkeley Mental Health present to our group. **Jeffrey Johns, MD,** is the Medical Director of the City of Berkeley Mental Health. **Terri King, MD,** is a Child and Adolescent Psychiatrist. We have asked them to give an overview of the medication issue, since it permeates compliance with interventions and recovery.

This will not be the time for personal medication consultation but a chance to get a bigger picture of this topic.

Speaker Meeting starts at 7:30 pm

The presentation will be **Zoom/online,** and attendees should preregister at our website: https://namieastbay.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://namieastbay.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.

Breaking Barriers Conference

It's not too late to register for the virtual conference Breaking Barriers: Resilience, Mental Health, and Hope, May 4, from 9am to 5pm. Offered by the Mental Health Association of Alameda County, the featured speaker is Brandon Marshall, Executive Chair of PROJECT 375, a nonprofit devoted to unlocking human potential.

There will also be presentations on Connection and Joy After Traumatic Stress, American Psychological Association Apology, Mental Health Diagnosis Across the Family, and Hip-Hop Therapy.

A highlight will be a panel discussion on Emerging Practices in Mental Health Crisis Response. Participants will be representatives from Denver STAR (Colorado), Familiar Faces Program (Washington), Mental Health First (Sacramento), and from Alameda County the Community Assessment and Transport Team (CATT), Mobile Crisis Team, and Mobile Evaluation Team.

Go to https://breakingbarriers.vfairs.com for more information and to register.

Book Recommendation

Colleagues in the mental health arena are raving about *Healing, Our Path from Mental Illness to Mental Health* by Thomas Insel, MD. Dr. Insel has long been a voice of reason, competency, and kindness in his roles as Director of the National Institute of Mental Health (NIMH) and most recently as a mental health adviser to Governor Gavin Newsom. As a psychiatrist and neuroscientist, he has been heavily involved in research, policy, and the use of technology. His book deals with treatments that can work if systems could deliver them effectively. The medical problems of mental illness are best treated by a combination of medical and social interventions. We respectfully suggest that all take a good look at this book. Local efforts are under way to try to bring him to the area for a presentation.

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SPEAKER NOTES

Mental Health Law: A Road of Potholes and Roadblocks

Summarized by Thomas T. Thomas

A family member, educator, activist, attorney, and Bay Area native, **Paula Aiello** is on the steering committee of Families Advocating for the Seriously Mentally Ill (FASMI). She originally gave this presentation to that group. Her talk covered the history of mental health laws and regulations from a global, national, state, and local perspective and offered a valuable framework with which to view our present conundrum. (**Note:** This is the barest outline of her richly detailed presentation, for the full Zoom recording, go to the NAMI East Bay website.)

Aiello pointed out that, while she is an attorney, she is not an expert in mental health law. But working with FASMI involves a lot of legal questions. "Mental health laws affect people in dramatic ways," she said.

The history of mental health before the 1960s involved warehousing people in prisons or shelters, like London's St. Elizabeth's Hospital—known as "Bedlam"—established in 1403. America began building asylums for the mentally ill in the 1800s, but still no treatments were available. In the 1950s, the asylums were full, with 2,000 people in Agnews State Hospital in Santa Clara. Before the 1960s, it was easy for someone to initiate a civil commitment process on an incapacitated person. Not until 1954 did the FDA approved the first antipsychotic medication, Thorazine.

Advocacy for the mentally ill at the global level began with the U.N. in 1948 and its Universal Declaration of Human Rights, whose Article 25 included medical care. The U.S. adopted this resolution but does not necessarily follow it. Other global agreements and the World Health Organization (WHO) support a right to health care, but so far the U.S. Supreme Court has not recognized this right.

At the national level, the United States follows the Constitution, legislation written into the Code of Federal Regulations, executive branch regulations and executive orders, and judicial branch opinions and rulings involving constitutional matters, federal statutes, and areas of conflict in individual state laws.

The Constitution is based on English common law and maintains individual freedom from involuntary detention or servitude, but it permits exceptions such as for criminal acts. It provides freedom to make choices about our lives but has exceptions for public welfare and for individual incapacity. It protects individuals from unrelieved state power with equal protection of due process and allows individuals to challenge detention with a writ of *habeas corpus*.

In 1949, the National Institute of Mental Health was established. In 1963, John F. Kennedy signed the Community Mental Health Centers Act, designed to deinstitutionalize patients and treat locally those who are a danger to self or others—but its provisions were never fulfilled. In 1964, the Civil Rights Act included mental health treatment for the gravely disabled. In 1965, Medicare and Medicaid were created, under which society assumes a share of responsibility for care of the mentally ill. In 1990 came the Americans with Disabilities Act (ADA), which protects against discrimination of the physically or mentally impaired and ensures they have the same rights as everyone else, and in 1996 came the Health Insurance Portability and Accountability Act (HIPAA), which provides for patient confidentiality.

A Supreme Court case in 1999 involving ADA resolved self-determination for people with disabilities, saying they could receive state-funded treatment in the community if a professional approves it, the person does not object, and reasonable accommodation can be made. But the ruling did not say the person *must* be held in the community. Each person is entitled to treatment in the most integrated setting with the least amount of restraint.

Medicare is a federal insurance program for people over 65, and those younger in some cases, regardless of income. However, it limits payment for treatment in a psychiatric hospital to 190 days over a person's lifetime—a limit that does not apply to medical care. Both NAMI and FASMI support repeal of this limitation.

Medicaid (in California, Medi-Cal) is an assistance program for people under 65 based on income and assets. It is co-run by the federal and state governments, and states can adopt and expand its programs. However, Medicaid has an Institution for Mental Diseases (IMD) exclusion that prohibits payment for patients in mental hospitals with more than 16 beds—which are most of the major hospitals like Alameda

County's John George Pavilion. States can seek a waiver, and California has one for substance abuse but not for serious mental illness. HR2611 seeks to repeal the IMD exclusion.

HIPAA was intended to protect release of a patient's sensitive information to health care providers, insurance companies, and employers. It permits giving information to families and caregivers, but many providers don't understand this. The patient can also sign a release but then verbally rescind it.

At the state level, California also has constitutional, legislative, executive, and judicial influences on mental health care. The largest was the Lanterman-Petris-Short (LPS) Act of 1967, which wrote into the Welfare & Institutions Code Sections 5150, 5250, and others. These were intended to end inappropriate involuntary detention and create a right to prompt psychiatric evaluation and treatment as a matter of due process. They apply to people who are "a danger to self or others or gravely disabled" and provide a series of staged evaluations with a hearing before a judge at the end of 72 hours and then after 14 days of detention. Involuntary use of antipsychotic medications is not permitted except in emergencies.

Gravely disabled is defined as "unable to provide for personal needs for food, clothing, and shelter" and is vague and inconsistently applied. A person clothing themselves out of a garbage can and eating roadkill is not considered disabled. California's AB2020 would amend this to include mentally ill people incapable of making informed decisions or providing for themselves without supervision and at risk of bodily harm, worsening condition, or psychiatric deterioration. It recognizes that a person with anosognosia—denying their illness—may also be gravely disabled.

Conservatorships for the mentally ill are complicated. Probate conservatorships are for people who can't make decisions—often the elderly—and are carefully monitored. LPS conservatorships are for people gravely disabled due to a mental disorder, are appointed a public guardian (not necessarily a family member), and the guardian cannot mandate psychiatric medications but can authorize involuntary placement in a licensed hospital or facility. In Alameda County there are just nine deputies serving as guardians, and each has a caseload of 40 to 50 patients.

The Mental Health Services Act (MHSA), based on Proposition 63 passed in 2004, levies a 1% tax on people with million-dollar incomes to build a fund for people with serious mental illness. The problem is that the money sometimes just replaces other funds that the county can now spend for other purposes. It is also susceptible to expansion, such as school programs intended to prevent mental illness and substance use disorders—which were added in a 2021 amendment.

In 2002, California adopted Assisted Outpatient Treatment (AOT) and is now weighing the just-proposed SB1338, which would establish CARE Court. This is a plan to provide services to the homeless with psychiatric disorders and allow another person close to the patient to petition for clinical evaluation and treatment. For details see CARE Court at the California Health and Human Services website. The state is also studying a proposed right to mental health care with SB1446.

Mental health care in California is provided by the counties, and Alameda County's record is not the greatest. There have been a number of lawsuits to correct this.

A case from 2018 was recently settled to improve the condition of mentally ill people in jails, with an order for the county to provide the sheriff's department and jail facilities with more funding and staff to treat patients.

Another suit, by the group Disability Rights California, seeks to correct the lack of community-based services. It says that John George is overused, and that lack of appropriate services leads to people being recycled through the system.

FASMI, in a protest early in March, demanded that the Board of Supervisors address the need for acute and subacute care beds in the county. With a population estimated at 1,685,000 and growing at a rate of 0.27% per year, Alameda is California's eighth largest county, yet it has only 200 hospital beds for psychiatric patients. Based on the best estimates of needed services, it should have more than 1,000 beds.

This is a situation we are all working to correct, along with housing, treatment, and patient advocacy.

If you have questions, you can contact Paula Aiello at paulaforjustice@gmail.com.

The full presentation recording is available on the NAMI East Bay website under What's New. Past Speaker Notes articles are available online at www.thomastthomas.com/NAMI.htm.

Musings

As I write this, I am sitting in a Brooklyn Airbnb on a visit with my daughter, who just opened her second cheese and wine bar. I am in awe of how much a change of setting and routine impacts my home-based routine of being triggered by so many things to ponder and worry about. Getting away helps, even more so—of course—when it involves amateurishly sitting in on a wine tasting with a bonafide wine company rep. It's a whole different world out here and I've been in conversations about small business ethics, customer satisfaction, staff scheduling, texture of cheese pretzel dough—the list goes on. And it's so different to not be thinking about crisis phone numbers, housing solutions, and families in stress. Which is not to say that I'm not surrounded by those very same issues right here in New York City. It's a matter of perspective.

Even among friends and colleagues in the Bay Area, perspectives vary so much. Although there are many, many similarities and overlaps, each of us views our situation with an ill family member differently. Our eyes focus on our internal priorities. I vividly recall the married university professors who were aghast that their child wouldn't have a college education. Others bemoan the lack of grandchildren or, more acutely, the fate of grandchildren being raised by a parent with mental illness. Many of our families are in the first throes of dealing with the chaotic behaviors of a newly diagnosed family member who is reacting with anosognosia and feeling there is nothing wrong but it is everyone else's fault. Other families have been through years of this experience and focus on the huge worry of what will happen when they are gone. Still others take the grief and anger and frustration they are experiencing and turn it purposively towards the system that is letting them down.

Some years ago, Elizabeth Kubler Ross wrote a well-received book on the stages of grief. There is a parallel span for our families, with the major difference being the ongoing issues of crisis, remission, interaction, and continual, ever-changing needs for problem solving. We teach in our Family to Family class that there is a final stage of acceptance. For many of us, that is debatable.

In the meantime, it behooves us all to take care of ourselves. Here again, it is different strokes for different folks. In our weekly support group, participants are asked to share about something they will be doing in the near future for fun and relaxation. For some, it is exercise and working out, for others it is yoga and meditation or nature walks. Some relax by socializing or engaging in hobbies. One of my favorite activities is that of the woman who watches the webcam soap opera of the peregrine falcons who nest in the Campanile tower at UCB. (Indeed, after a robust discussion last night about the birds' lives, one participant remarked that we were having a peregrine falcon support group).

I don't know quite how to end this column since I don't really know where it has been going. But sitting here, on a drizzly New York City day in a world quite different from the world I regularly inhabit, my musings are of how we are going through life on such different paths. It's a painful process for many of us for a slew of different reasons, but we're all in this together … Carry on.

—Liz Rebensdorf, President, NAMI East Bay

New Crisis Hotline

On July 16, 2022, a new National Mental Health Crisis Hotline, by dialing 988, will be launched. Towards this end, a highly impressive collaborative of leading mental health professional organizations and advocates is coordinating efforts to drive awareness and support among state and municipal officials. This represents a transition from the current National Suicide Prevention Lifeline to a hotline for comprehensive mental health emergencies and suicide prevention.

The leadership collaboration is made up of 15 chief executive officers (CEOs) with the title CEO Alliance for Mental Health. It includes leaders from the American Foundation for Suicide Prevention, American Psychiatric Association, American Psychological Association, Mental Health America, National Alliance on Mental Illness (NAMI), and Treatment Advocacy Center among others.

Goals for local services include early outreach and engagement of people at risk, call center hubs staffed with trained crisis counselors, mobile crisis teams, community-based treatment clinics, in-patient psychiatric facilities, housing facilitation, and post-

crisis support.

Locally in Alameda County, a 988 Collaborative has been developed to foster systemwide coordination. Calls to the Crisis Support Services will be triaged 24/7.

An excellent overview is given at the website https://wellbeingtrust.org.

Mental Health Apps

A recent (4/13/22) *New York Times* article, "How to Find a Mental Health App That Works for You," explores the issue of trying to find an inexpensive way to get help in light of difficulties with cost and finding therapists. This problem is compounded by the pandemic and the relative unavailability of providers in rural areas. The article brings up the fact that most of the 10,000 apps out there are unregulated and may have "shaky (or nonexistent) privacy policies."

Experts in the field note that apps can help people gain insights into the interaction among thoughts, feelings, and actions and help facilitate the skills learned in therapy. For stress, apps can help users with deep breathing or meeting physical exercise goals. But they are not sufficient if an illness is moderate or severe or if the person isn't motivated.

We asked our own in-house expert to comment on the article. Michael Godoy is Program Director, Telemedicine and Scalable Therapies, UCSF, and a member of our board. His comments follow:

"Digital mental health apps aim to address barriers to conventional therapy that include:

1. Physically being in an office,
2. High cost, and
3. The relatively small number of available mental health professionals for the 1 in 5 people that have a diagnosable mental illness.

"The promise of digital mental health apps is that they are a scalable, asynchronous method to learn the same skills and tools you would learn with a therapist at your own convenience. However, not all such apps adhere to evidence-based interventions and most that do cannot maintain a high quality of service due to the varying needs of the populations that can benefit from such an app. The ideal mental health app is not only based on evidence-based interventions, but the health outcomes of the app are well studied, and the app personalizes the resources it delivers to you based on what you need and when you need it. The ideal use of a digital mental health app is alongside therapy with a professional and not as an emergency service.

"Digital mental health apps developed and studied by the government like PTSD Coach, Mindfulness Coach, and CPT Coach are highly recommended due to the adherence to these principles and no charge for use."

Excerpts from *Psychiatric Times*

- **Antipsychotic Nonadherence in Schizophrenia (4/18/22):** One in three outpatients with schizophrenia were noncompliant with antipsychotic drugs, compared to somatic medications. Adherence rate was highest with Clozaril and with long-acting injectables.
- **Prodromal Mania and Psychosis (3/28/22):** In a study of first-episode mania (FEM) and first episode psychosis (FEP), "Risk/vulnerability markers include a family history of mood disorders and attention-deficit/hyperactivity disorder for bipolar disorder, perinatal complications, worse premorbid adjustment, and increased cannabis use in schizophrenia." Social isolation was associated with FEP and increased energy with FEM.
- **Psychiatric Care in the US: Are We Facing a Crisis? (4/1/22):** "By the end of 2021, many Americans found themselves in the worst mental state in years … 47% of adults reported symptoms of anxiety, 39% reported symptoms of depression, and 1 in 5 adults disclosed suffering from a mental illness … less than half of American with mental disorder get adequate treatment." Some factors discussed include, of course, Covid-19, teleworking, economic and social upheavals, bureaucratic and insurance demands, costs, and availability of mental health providers. The article presents a state-by-state comparison and notes that another factor is a community's ability to openly discuss mental health concerns and be less judgmental. There is more use of telemedicine and gradually more reliance on physician assistants (PAs), nurse practitioners (NPs), and psychiatric mental health nurse practitioners (PMHNPs).

NAMI East Bay

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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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