NAMI EAST BAY NEWSLETTER

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

September-October 2021

Advocacy in Alameda County Panel Discussion

Wednesday, September 22, 7:30 pm

We are so pleased to present an overview of mental health advocacy in Alameda County. (Readers from other counties will benefit as well, as there are many areas of overlap). Topics to be presented include an overview of current state and federal legislation, an explanation of how the Alameda County Behavioral Health Care System operates regarding funding and decision points, a description of advocacy actions we all can take, and an update on Families Advocating for the Seriously Mentally Ill (FASMI).

The Zoom platform doesn't incorporate a long table with discussants sharing their expertise; so this will be slightly different. Participants include persons knowledgeable about legislation, a representative from the Office of Family Empowerment, and founding members of FASMI. Please join us.

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 form 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." Or you can register here via Zoom.

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.

Discussion Group on Patients' Rights

Wednesday, October 27, 7:30 pm

Our Fourth Wednesday online discussion group in October will address the subject of patients' rights. Francesca Tenenbaum, director of Patients' Rights Advocates, will share with us about their mandated responsibilities for patients under involuntary detentions and the handling of violations and concerns. Registration will be available on the NAMI East Bay website.

Future Planning Discussion from June

Our Fourth Wednesday online discussion group in June addressed the topic of planning for our ill relative when we parents are not present. We had around 15 participants and it was a robust discussion, accessible via the video recording posted on our website under "What's New." In short, we discussed data needed around: (1) independent functioning; (2) personal management through a private case manager or insurance and In Home Support Services; (3) finances through fiduciary assistance and special needs trust; and (4) housing options.

Family to Family Class in January

We will again be offering our eight-week Family to Family class starting in mid-January. These free, two-and-a-half-hour classes for family members cover the whole topic of mental illness (diagnoses, meds, coping, communication, brain function, etc.). Please let us know if you are interested in joining. As of right now, we are not sure whether this will be an online class or in person at our site in Albany.

In the meantime, there is a class being offered by the Family Education and Resource Center (FERC) starting September 30. To register or for more information, contact jisegen@mhaac.org or evalle@mhaac.org.

The NAMI EAST BAY NEWSLETTER is published bi-monthly, beginning in January, by NAMI East Bay, 980 Stannage Ave., Albany, CA 94706.

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SPEAKER NOTES

Telehealth and Changes in Mental Health Care

Summarized by Thomas T. Thomas

Dr. Kim P. Norman, MD, is the Distinguished Chair of Adolescent and Young Adult Health at the University of California, San Francisco, and a psychiatrist with over 40 years of experience caring for young adults and families with mental health challenges.

In 2004, he founded the Telemedicine and Scalable Therapeutics Program at UCSF's Department of Psychiatry and Behavioral Sciences, where troubled young people and their families receive the best available clinical care, irrespective of their ability to pay. He has also pioneered new, scalable, and personalized approaches to psychotherapy like GritX.org.

"What keeps me awake at night," Dr. Norman said, "is that if all my patients are doing well, then I'm not taking on enough challenges." He explained that he can only see about ten patients a day, or seventy in a week. Even though he takes on patients who need help the most—those with schizophrenia, bipolar disorder, suicidal ideation, etc.—he still gets calls from patients with severe mental illness, and from their parents and friends, who need help.

This led him to develop GritX, which consistently scales evidence-based services in an online format. It is available to thousands of patients—the current usage is about 2,500 per day—without the barriers of insurance costs, "consumable" hours[1] of professional time, and cultural differences. The process is "asynchronous," because the patient gets therapy in his or her own timeframe, rather than at the pace of individual sessions with a human therapist.

With that introduction, Dr. Norman opened the discussion to questions.

Q. What evolution have you seen in the field of psychology in your lifetime?

By the 1970s, psychoanalysis—which focuses on early childhood experiences and traumas—had passed its peak as the dominant model. This focus had suggested that bad parenting—the "schizophrenogenic mother"—was the source of most mental illnesses.

"When I was in training," he said, "there was a lot of arrogance. You come into my office, pay a big fee, and spend hours and hours talking about yourself. But people learn and grow in all different ways, and you have to respect that."

Medical schools since World War II have divided their departments, and specialties like cardiology and nephrology, into general medicine and surgery. In the same way, psychology became divorced from neurology, which separated the study of the mind from its underlying organ, the brain—like separating ophthalmology from the study of the eye.

But the 1970s were also the beginning of the biological revolution, where mental illness was treated on a biopsychosocial model. "Biology plays a tremendous role in behavior," Dr. Norman said, "as does neurochemistry—leading to remedies in pharmaceuticals—and in physical approaches such as electroconvulsive therapy [ECT] and transcranial magnetic stimulation [TMS]. There are also social implications, like trauma and post-traumatic stress disorder."

Also, we now know that a lot of psychotherapies don't require intensive, one-on-one sessions—for which there are not enough hours in the day or quality control with evidence-based practices. For example, cognitive behavior therapy (CBT) focuses on how a person thinks, feels, and acts. It shows the person that the reaction to a negative situation ("I'm a loser") can be turned into more positive thoughts ("I wasn't prepared" or "You win some, you lose some").

One scalable form of therapy is self-help books like David Burns, MD's *The Feeling Good Handbook*. But many people might buy it and not read it, or read the first chapter and then stop. So using such a tool in the context of a support group or online discussion is more helpful.

Q. How do you know when to get therapy and when to get medication?

You don't have to be in crisis to talk to a therapist—although these days, with insurance paying for the cost of treatment, it is too common for a doctor's referral to be sent automatically to the emergency room, as if it were a 5150 with an involuntary hold.

If you can't "stay in the moment," if anxiety or depression is keeping you from functioning, if you can't regulate your emotions, then you want to talk to a psychotherapist. In the current healthcare system

[1] "Consumable" hours are those that a therapist devotes to sitting one-on-one with a patient, while "non-consumable" time would be that invested in writing a self-help book or online service which thousands of patients can access on their own.

this usually begins with a psychologist or social worker. If you still are suffering, then you will want to meet with a psychiatrist, who can prescribe medications.

Q. How do you find a psychiatrist?

You can get a referral from a friend or a professional like a school counselor. *Psychology Today* offers listings by location and specialty. But it's best to meet the person and trust your gut. Ideally, the psychiatrist will offer a free introductory interview where you can decide if he or she is a good listener, asks questions or makes comments that give you an "aha" moment, or challenges you to know yourself better.

Q. How do you deal with patients exhibiting anosognosia, denying that they are sick?

Denial is a form of self-deception, and it may be based on fear of stigma. So if a patient denies being mentally ill, you can focus on problems that the illness may be causing, like relationships with other people, ability to focus and concentrate, and functioning at school and work.

Q. Can cognitive behavior therapy (CBT) be used effectively with obsessive/compulsive disorder (OCD)?

OCD is a brain disorder but arises from an important human need to pay attention and take care. We are all born prematurely and need a mother's obsessive care to survive in the wild. And, for example, good doctor is obsessed with the care of his patients.

But when the mechanism for caring becomes excessive—checking the stove repeatedly, washing your hands seventeen times, so that it interrupts your day—then CBT can help you with controlling your thoughts and with breathing exercises.

Q. Tell us more about the GritX program.

NAMI East Bay's Michael Godoy, who helped develop the program, stepped in to explain. GritX gives the user everything they could learn in personal therapy but without the time and cost.

1. **Skills Studio** starts the program with a self-care book that is constantly being updated with evidence-based practices, which are cited in references. It is written at a sixth-grade level and includes illustrations. The skills help the person with emotional regulation, life challenges, and various scenarios. It includes a Body Scan that links to other sections of the program.
2. **Self-Interview** is an interactive dialog reflecting the person's life situation. For example, it may ask the person to select an object and focus on it to become grounded. This part of the program includes free responses and fill-in-the-blank statements.
3. **Self-Care Toolkit** asks the person what things make them feel good on a daily basis.
4. **Journaling** provides prompts that let the person put their feelings into words.
5. **Sketchbook** works like journaling, but for those who are more visually oriented, with drawing aids and stamps.
6. **Catch Your Breath** includes tools for breathing and meditation.
7. **Expedition** takes the best content and skills, based on specific life challenges, and integrates them into a course for the person.
8. **Chat** is an emotionally intelligent bot—in beta version, but it's learning everyday—that engages in a relationship between a good friend and a therapist.

GritX is also available as a downloadable application that includes the website's content and materials for personal use or for use with others.

Q. What is the connection between psychology and autoimmune disorders?

This is an emerging field. We know that antibodies can affect the brain, and that viruses can cause post-acute conditions. There is still much to learn here.

Q. What mental health issues do you expect after the COVID-19 pandemic?

In a normal year, 10% to 12% of people express anxiety complaints. During the pandemic, that rose to 40% generally—and 56% for teens and young adults, who have lost school and social activities. Additionally, "long COVID" creates inflammation and "brain fog" in some patients.

This is different from a single mass disaster, like a flood or earthquake, where after six months 90% of those involved get over it. With COVID—where your best friend can kill you at any time—only 60% of people are returning to normal. One percent of the population has lost a close relative to the disease. Others have experienced trauma and express it as grief. And now the Delta variant is resurfacing those fears.

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

Families are so visibly relieved when they share that their relative is "finally in therapy." In today's reality, this generally means a 20- to 45-minute individual talk on a varied schedule from once a week to once a month with a trained therapist—oftentimes at substantial cost. Details depend on specificity of target issues or problems, specialties of the professional therapist and—bottom line—insurance coverage.

Our August speaker, Dr. Kim Norman, has a provocative take on therapy which is worth delving into further here. (Notes on his presentation are shared in this newsletter and the August 28 meeting is video recorded and accessible on our website under "What's New"). Essentially, his message was that a bit of arrogance underlies the concept of therapy and that, indeed, all sorts of experiences can lead to growth or "aha" experiences.

We in the Bay Area enjoy a plethora of trained therapists to choose from, although in this pandemic age those resources are becoming scarcer as anxiety and depression and need for therapy increase. Nevertheless, the amount of choices open to us urban folk contrasts with the lack of services available in areas away from the cities. That is why Dr. Norman has been exploring alternatives to face-to-face therapy and why he recommends David Burns's *Feeling Good Handbook* and the website www.gritX.org, which are described more fully in the Speaker Notes and recording.

For those of us with relatives with mental illness, the notion that everything is a growth experience is both a blessing and a challenge. Families are already burdened with the practical logistics of caretaking and providing for housing, food, clothing, etc. Now, here we are being told that we're also the therapists … but really, you already know that. Look around.

Consider how you choose certain words when you communicate, how you stifle your irritation and impatience at times, how you strive to be supportive and empathic, how you help your relative express him- or herself more clearly, how you intuit when to just sit silently. These are all acts of therapy.

Other acts of helping, which is the definition of therapy, include just engaging over any topic or taking a walk or singing a song together. These are all socializing actions. The modeling of coping skills is therapy, and that would be such behaviors as retreating, clarifying thoughts and emotions, rewording, prioritizing, etc.

Of primary importance is your modeling of self-care, whether it be yoga, massage, deep breathing, hiking, or sitting under a redwood tree. This is not only modeling self-care but is also accomplishing your own necessary self-therapy.

Family members are not trained therapists, but we can certainly provide help.

—Liz Rebensdorf, President, NAMI East Bay

An Advocacy First Step

A family member asked me recently how he can actually change the world. Now it's hard to tell. We family members have been trying to change the world for years. In some ways it's been getting worse—fewer and fewer beds and board-and-cares or other suitable housing. And in some ways it's getting better—some journalists and elected officials do understand now that serious mental illness is a medical issue; it causes terrible suffering and disruption; it needs treatment; and many people affected by it are too ill to know they need help. And there's hope that the latter insight will grow and reverse the trend of trying to wish away serious mental illness and facilities to deal with it.

1. Tell your story. There are several things you could do with your story:

- Share it with your county supervisor and other elected officials and tell them what helped and what hasn't helped.
- Make it into a letter-to-the-editor after some news event.
- Make it into an op-ed.
- Include it in a book like *Tomorrow Was Yesterday* by Dede Ranahan.
- Make it into a video.

2. Help Families Advocating for the Seriously Mentally Ill (FASMI) organize into a diverse group with a simple message and take our message to elected officials. Learn who your state, federal, and county representatives are—especially county, because the county is responsible for keeping your loved one alive and well, if anyone is. Come with us when we get meetings with these elected officials.

3. Every once in a while, you can show up at meetings of bureaucrats, like the Mental Health Advisory Board, and use the opportunity to tell them what isn't working. There are innumerable state bodies also, like the Mental Health Services Act Oversight Committee, that rarely hear from us, though they often hear from disability rights groups. We can use Zoom to drop in and remind them of something they have forgotten.

4. Take advantage of occasions—state and federal legislation being proposed, or budget discussions going on—to practice telling your story. Say what *has* helped and what *hasn't* helped.

5. If you want, take advantage of county budget discussions and tell your story to the supervisors in writing or in person. Tell them what the county needs to spend money on. Particulars matter. Your story matters.

—Alison Monroe, FASMI

NAMI California Conference

The annual NAMI California Conference will be held virtually on October 14-15, 2021. To see the comprehensive list of speakers, topics, and event details, go to https://namica.org and follow the links to conference registration.

COVID and Serious Mental Illness

Research (per the Treatment Advocacy Center report 8/4/21) is showing that persons with serious mental illness (SMI) are a high-risk group in the fight against the COVID-19 virus. Based on an international review of 19,000 patients with both a SMI diagnosis and the virus infection, it was found that there was an increase in the likelihood of dying at a rate 1.67 times that of people without the psychiatric diagnosis. Several factors have been implicated in this finding such as healthcare access and social factors, along with comorbidities such as smoking, obesity, and substance abuse.

But another significant question is raised related to these findings and that is regarding immunological differences and the medical impact they create. We plead with researchers to further explore this area. The book *Hidden Valley Road* by Robert Kolker, about a family with six children diagnosed with schizophrenia, devotes a large amount of space to the search for answers, with generally inconclusive results. In some cases, the provocation leading to specific research was the exploration of a coincidence, a synchronicity. Why are our ill relatives becoming sicker with this?

There was some recent fuss made and, fortunately, individuals with SMI were moved up in the line to receive vaccines. Around the same time, a new relevant book came out, *The Angel and the Assassin* by Donna Jackson Nakazawa. It examines the impact that microglia, immune cells in the brain, have on everything from depression to Alzheimer's Disease to psychosis, described as a "paradigm-shifting reading for all of us." We can only hope that the scientific world can turn its attention to this area of inquiry regarding the immunity factor.

Providers for Diverse Communities

We live in a wonderfully diverse community with neighbors and friends from around the world. Here is a list of resources available for client-specific communities and their county service area (N-north county, S-south, C-central). Google them and check their websites for more information.

- Afghan: International Rescue Committee (N), Afghan Coalition (S).
- African: Partnership for Trauma Recovery (N).
- Asian - East: Asian Health Services (N), Korean Community Center of the East Bay (N), Tri-City Health Center (S).
- Middle Eastern and Arabic: Diversity Health in Training Institute (N,C).
- Native American: Native American Health Center (N,C).
- Native Hawaiian and Pacific Islander: Richmond Area Multi-Service (N,S).
- Filipino: Filipino Advocates for Justice (C,S).
- South Asian: Hume Center (countywide).
- Southeast Asian: Center for Empowering Refugees and Immigrants (countywide).

NAMI East Bay

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Please check your mailing label. If the code "21" is over your name on the right side of the label, your dues are current through 2021. If your mailing label indicates a previous year, or nothing at all, your dues are not current.

We urge you to mail your 2021 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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