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# NAMI EAST BAY NEWSLETTER

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

September-October 2020

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## The Relationship Between Sleep Disorders and Mental Illness

Wednesday, September 23

**Catherine Callaway**, a doctoral student in the Clinical Science program at the University of California, Berkeley, is part of the Golden Bear Sleep and Mood Research Team and is certified in sleep coaching. Topics covered at our September 23 meeting will include sleep basics, the relationship between sleep and mental illness, TranS-C (a new treatment approach designed to treat a wide range of sleep problems in individuals with mental illness), and a summary of tips for improving sleep.

Callaway is interested in researching how we can effectively translate psychological treatments developed in academic settings into the “real world” to reach the most underserved in our communities. Before coming to Berkeley, she worked at Massachusetts General Hospital in Boston with the Cancer and Mental Health Collaborative. She managed multiple projects focused on improving health outcomes for individuals with serious mental illness and cancer.

### Speaker Meeting starts at 7:30 pm

The September presentation will be **Zoom/online**, and we are asking attendees to preregister. Go to our website <https://namiestbay.org>, click on “What’s New,” and follow the link.

**Note:** The September meeting will be recorded both in written form, for the next edition of this newsletter, and as a video recording 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://namiestbay.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 a group. Check out your App Store, or Google “Zoom” and go to [Download Zoom](#).

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## Housing Option

We’ve mentioned the Independent Living Association previously and you may want to take a look at its updated website at [www.ilacalifornia.org](http://www.ilacalifornia.org).

This is housing similar to the boardinghouse model, where there is shared living and meals are provided. Tenants are able to live independently, are often on a fixed income, and do not need supervision or care from their landlord. Through the ILA, owners and operators are given training in all aspects of operating an ILA home. Introductory training is also available to those who are contemplating opening an ILA home.

For further information, go to the website or contact [alameda@ilacalifornia.org](mailto:alameda@ilacalifornia.org).

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## New Harbinger Publications

NAMI East Bay has been the fortunate recipient of some books from this local book publisher New Harbinger Publications. Unfortunately, because of the coronavirus, we don’t have access to our office but do want to recommend this publisher. The company publishes proven-effective self-help books and workbooks, as well as professional books on topics in psychology, health and personal growth. The website [www.newharbinger.com](http://www.newharbinger.com) is rich in materials for both families and individuals with mental illness.

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SPEAKER NOTES

## “Trauma Informed Care” – How It Transforms Therapeutic Care

Summarized by Thomas T. Thomas

“Trauma Informed Care” is considered a best practice in the therapeutic treatment of clients with severe mental illness. Alameda County Behavioral Health has mandated training in this approach for all of its service providers and staff. At our July 22 meeting, two speakers explained the practice and discussed its benefits. **Lori DeLay, LCSW, RD**, is the Training Officer for the Mental Health Services Act in Workforce Education and Training. She is also a family member. **Kelly Robinson** is a trainer with Alameda County Behavioral Health and an international coach for Trauma Informed Care.<sup>1</sup>

“The goal of the program,” DeLay said, “is to create a trauma informed system that fosters wellness and resilience for everyone—consumers and providers—at Alameda County Behavioral Health.”

Trauma and toxic stress figure among the six leading causes of death in this country, including heart disease, cancer, lung disease, cirrhosis, accidents, and suicide. People share the effects of trauma and stress at home and at work, creating a ripple effect. Under-resourced communities, such as those in poverty or affected by racism, also create stress. And stresses can be intergenerational as well.

The goal of trauma informed care is to transform the organization from being traumatized, stressed, and inducing these conditions in staff and clients to reducing them for everyone. A *trauma reactive* organization is fragmented, where no one feels safe, it is rigid and does not evolve. A *trauma healing* organization is integrated, reflective, collaborative, flexible and adaptable, equitable and inclusive.

This type of care shifts the therapeutic question from “What is wrong with you?” to “What is happening to you?” This shift provides context, fosters compassion, and establishes the person’s and the organization’s strengths in the face of adversity.

The six guiding principles of a trauma informed

organization are:

- Trauma Understanding
- Cultural Humility and Responsiveness
- Safety and Stability
- Compassion and Dependability
- Collaboration and Empowerment
- Resilience and Recovery

### Trauma Understanding

Individual trauma—and this can affect a single person, families, communities, and cultures—results from an event, a series of events, or a set of circumstances. The event creates an experience that leaves an effect. Trauma creates a “flight or fight” reflex that cannot be fulfilled, creating a sense of helplessness, overwhelming brain and body, and leading to disintegration and dysregulation with lasting adverse effects.

Stress can sometimes be good: challenging us, raising our heart rate, making us feel alive. That’s positive stress. We can tolerate many stresses if we have supportive relationships. But toxic stress, chronic stress, without support or recourse, is damaging. Unaddressed, it can suppress the immune response, increase inflammatory diseases, and lead to obesity.

Adverse childhood experiences, such as physical and emotional abuse, emotional neglect, witnessed violence, incarceration of a household member, and community experiences of poverty, disruption, poor housing, or lack of affordability, can lead to tension-reducing behaviors like drugs and alcoholism, risk taking, and self-injury. Experiencing enough of these stress factors can actually shorten a person’s life.

### Cultural Humility and Responsiveness

Socio-cultural trauma includes an atmosphere of assault and violence, both physical and sexual, inadequate medical facilities, and recurring incidents of racism, sexism, ableism, and other “-isms.” Individual and interpersonal, historical and structural incidents create synergistic trauma. So the idea of social and racial justice is central to trauma informed care.

“Structural racism,” DeLay said, “is historical, socio-cultural, and institutional. If one is affected, then all are affected. In this situation it is most important to ask ‘What is happening in the community?’ in order for people to become aware, gain context, express compassion, and see the community’s strengths.”

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<sup>1</sup> The curriculum they presented was adapted from one developed by the San Francisco Department of Public Health, and

they invite NAMI members to provide their own input and feedback.

People have different realities, she noted. Every home is different, starting with the parenting style and overall situation. Trauma informed care shifts from notions of equality, where everyone gets the same opportunity despite differences in situation and handicaps, to notions of equity, where everyone gets what he or she needs to overcome obstacles, depending on the individual's situation. Eventually, this leads to liberation, where the obstacles are deemed nonexistent.

### **Safety and Stability**

When people feel safe and in a stable situation, they can minimize stress and focus on wellness. Physical safety is protection from harm, refusal to tolerate violence, and reduction of unnecessary tension. Social safety involves building positive relationships. Emotional safety is building skills to manage one's own emotions, learn new ways of coping, and being safe within one's own self.

Stability comes from building a set of positive routines and creating a predictable environment. Stability makes you feel safe and well.

### **Compassion and Dependability**

"Trauma can make us feel overwhelmed, isolated, and betrayed," Kelly Robinson said. "Compassion means being able to hear about another person's situation in a nonjudgmental way. Dependability means that the person is able to trust us. And that they can be so for us." She defined "co-regulation" as two people being in a compassionate and dependable relationship, so that they help each other through their own energy, reducing stresses and healing the trauma rather than aggravating them.

Robinson showed an animated video that differentiated between empathy and sympathy. Empathy involves taking the other person's perspective, avoiding judgment, recognizing that person's emotion and recalling those feelings within oneself, and communicating all of that. Sympathy, on the other hand, is too often an attempt to offer a solution, "make things better," or create a silver lining: "Well, at least you've still got your health." Empathy means being vulnerable to share in the other's emotion, accept it as their truth, and acknowledging "What's happening."

### **Collaboration and Empowerment**

Trauma involves a loss of personal power. That power is returned when we are prepared for and given the opportunity to do something for ourselves and our own care. So trauma informed care promotes people's

ability to meet their own needs, solve their own problems, and mobilize the necessary resources to feel in control.

The relationship between consumer and provider is one of partnership. The consumer and family members have choices in the care process. The consumer can make his or her own plans and evaluate services. And the consumer and family member develop skills, strengths, and resilience that are recognized and supported, and upon which the consumer can build.

### **Resilience and Recovery**

Trauma and stress can have broad, long-term effects on our lives and create feelings of helplessness. When we focus on our strengths in adversity, we can take steps toward wellness. Resilience is the process of adapting in the face of adversity.

Gaining resilience involves both the mind and the body. Self-care involves physical movement, tactile experiences, and breathing exercises. It involves doing one thing at a time. It means finding an activity that you love and then *doing it*. It means building good eating and sleeping habits. It means getting outside and breathing fresh air.

Resilience also involves developing a sense of gratitude—for your own well-being, for your relationship with others, for new possibilities in your life.

Recovery is the process of change through which the individual improves his or her health and wellness. In essence, the person moves from "What's wrong" to "What's happening" to "What's strong in you?"

For more on available East Bay programs, refer to <https://AlamedaCountyTraumaInformedCare.org> and <http://traumatransformed.org>.

The speakers then invited questions.

### **Q. A psychotic break is itself traumatic. Does trauma informed care consider that?**

A. The staff trained under this program treat people with severe mental illness, including psychosis.

### **Q. County services are fragmented and hard to navigate, with services in different offices.**

A. We are aware of how these systems can induce their own kind of stress and trauma. There's no easy answer for that, and fixing it will take time.

Past articles in the Speaker Notes series are available online at [www.thomasthomas.com/](http://www.thomasthomas.com/) under "NAMI East Bay." Also available is a copy of the brochure "Medications for Mental Illness."

### Musings

In the support groups that I've been facilitating for some years, there is a fairly common pattern. At the risk of generalizing, we spend some time on diagnoses and the essence of mental illness, some time on medications, some time on resources, some time on self-care ... but, by far, the most time is spent on practical problem solving. How does one live or interact, on a daily basis, with a loved one who has a mental illness?

These are not the episodes of full psychosis, with which we often need outside help. These are the issues involving such concerns as nutrition, hygiene, anger control, use of time, safety, medication compliance, willingness to accept help, acknowledgment of the mental illness, communication, etc. It is these frequent areas of conflict which wear down the reserves, patience, and resilience of family caregivers.

For those of us with a firmer grasp on logical reasoning, our internal resources are stretched way out beyond our comfort zone when we deal with our relative who has some emotional dysregulation or disordered thinking. In support groups, we brainstorm some of these situations, and it is clear that what works for one person may not work for another, or what works well on a Tuesday may not be feasible on Wednesday or next week.

Often, families who join our groups in crisis or stress slip away when problems are temporarily solved. So we don't hear much about successful strategies or the use of "family wisdom," as one board member described it.

There are many well regarded books out there by experts which deal primarily with communication strategies, and those are successful when used by a family member who is comfortable with a technique and dealing with an ill relative who is responsive. There are other books which address behaviors and how to productively cope with them. Frequently, these are written by credentialed experts who see clients in a controlled therapeutic setting. Nothing wrong with that, but where were they when your son took the hinges off the door to get into the house?

And that's where you, our readers, come in. We at NAMI East Bay propose to put together a publication, size to be determined by amount of material, on practical coping techniques. And we invite your

input. This need not always reflect your successes—sometimes ideas that sound really good on paper did not work with your relative but may with another person. We want to hear all of those ideas and strategies, successful or not. Some of my best brainstorms in dealing with my son's OCD behaviors stayed solely in my brain since they certainly had no access to his.

Some examples of issues might be: How did you get your daughter to wash her hair after six weeks? How did you convince your son to eat something besides junk food? What do you do when your daughter explodes over a minor incident and verbally abuses you? How did you handle your son not leaving his room all day? The list of questions goes on and on.

With a target date of an October wrap up, we are hereby calling for your submissions of positive and negative strategies. You can submit one or twenty-plus items and we'll keep it all anonymous. We are sending this out to local families, and when we see what comes in, we'll plan the organization of the material. Feel free to distribute this request to family and friends.

Please send submissions to our email, [namieastbay@gmail.com](mailto:namieastbay@gmail.com), with the subject line PPS or Practical Problem Solving.

—Liz Rebensdorf, President, NAMI East Bay

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### Options for Taking Action in These Stressful Times

For many of us, the lack of control over our situations has been highlighted by the parameters set forth by the coronavirus pandemic. Add to this the stress and anxiety of dealing with a loved one's mental illness. For many, the role of being a passive bystander in this chaotic time is intolerable. If you're coping with a totally different lifestyle where the hours may stretch out and you feel bored, anxious, or depressed, there is an antidote.

Join an advocacy effort. The system has shortcomings, some based on the realities of regulations and finances, and some based on shortsightedness or lack of commitment to systemic change. There are numerous efforts being made to advocate for improvement; some advocacy is more organized and

some more family-oriented than others.

We at NAMI East Bay participate in or know of groups focusing in on such topics as county issues, state legislation, housing, or treatment options. Sometimes advocacy involves engagement in problem-solving discussions or presentations to the Board of Supervisors, and sometimes it means writing letters or making phone calls to state legislators.

Do some self-reflection and determine which concerns are most important, based on your lived experience and knowledge. And then send us a note at [namieastbay@gmail.com](mailto:namieastbay@gmail.com) and we'll suggest different advocacy groups which might be of interest to you.

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### Online Alternative Support Resources

Our goal is to offer support to our readers, and we understand that not everyone is comfortable with traditional support groups. So here are some free alternative options:

- **Bay Area Hearing Voices Network** groups for people who see, hear, feel, or think things that others do not experience. Separate groups are available for peers and for friends and family members. Groups are online Mondays 6-8 pm. Go to [www.bayareahearingvoices.org](http://www.bayareahearingvoices.org) for access information.
- **Tele-mental health** through [www.gritx.org](http://www.gritx.org). Our board member Michael Godoy has been instrumental in the UCSF development of this website. This psycho-educational site helps youth and their families explore issues around mental health and build resilience, using internal and external resources.
- **AFIYA Care - [Roots Community Health Center](#)**, focused on African-Americans, provides specialty mental health services regarding the criminal justice system and incarceration. Weekly individual counseling and support groups are offered.
- **Using Energy Medicine, Energy Psychology, and Sound Healing**, your nervous system will find calm, ease, and resilience while building up your immune system. *Calm Your Nervous System*: Mondays at 7 pm PDT. *Calm Financial, Livelihood Worries, and Everything Else Distress*: Thursdays at 6 pm PDT. Both are accessible by Zoom; all are welcome to attend both or either day. It's best to have a headset or headphones for the sound

portions. This group is led by Rachel Michaelsen, LCSW. For more information, go to [www.rachelmichaelsen.com](http://www.rachelmichaelsen.com).

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### OCD Research Advances

Obsessive-compulsive disorder (OCD) falls under the umbrella of anxiety disorders and often imparts a bigger impact on behavior than an underlying mental illness.

Research reported on [WebMD](#) suggested that OCD may be linked to inflammation in the brain. A small 2017 Canadian study found inflammation was 32% higher in six brain regions associated with OCD. About 1% to 2% of teens and adults have this disorder, and current meds fail to help nearly a third of OCD patients. An inquiry we made to a psychiatrist regarding implications for medication has not yielded a response. (*JAMA Psychiatry*).

The neurobiology of OCD is explored in a *Psychiatric Times* article July 2020. Concluding remarks about the meta-analysis include, "OCD is often associated with structural brain change ... functional imaging has revealed hypo-activation during tasks of inhibitory control ... cognitive and neural changes have also been identified in first degree relatives of patients who have OCD ... may reflect some biological associations constituting vulnerability markers ... first-line treatments have essentially remained unchanged for at least 30 years ... longitudinal research is needed."

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### Expanding Brain Research

In the latest edition of [Science magazine](#), Viviana Gradinaru of the California Institute of Technology describes various techniques for direct research on the brain and treating brain disorders. Her article describes various approaches including penetrating the blood-brain barrier; using light-sensitive proteins introduced by adeno-associated viral (AAV) vectors; overcoming the neuronal and brain-centric view of neurological disease; and modulating the peripheral nervous system to address central dysfunction. Her essay was grand-prize winner of the Science-PINS Prize for Neuromodulation.



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We urge you to mail your 2020 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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