
NAMI EAST BAY NEWSLETTER

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

May-June 2021

Laws We Need to Know: Understanding Rules and Programs for Persons with Mental Illness

Wednesday, May 26, 7:30 pm

This [new book](#) was written by San Francisco attorney **Baron L. Miller** (www.baronmillerlaw.com), a long-time NAMI member, friend of NAMI, and an advocate who has an adult daughter with schizophrenia. He has practiced law in San Francisco continuously since 1973 and is a frequent writer and lecturer on legal issues faced by family members of mentally ill persons. He has been advising and assisting clients and other attorneys on these issues for decades.

The book covers—and he will discuss—such topics as government programs and benefits, estate planning, the criminal court system, hospitalizations, restraining orders, and family liability. He also suggests strategies to use with authorities. The book further explains federal laws, procedures, and programs pertaining to persons with mental illness and explains and uses pertinent California laws as a model for most state laws.

Speaker Meeting starts at 7:30 pm

The May presentation will be **Zoom/online**, and attendees should preregister at our website: <https://namiestbay.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://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 the group.

Discussion Group on Long-Term Planning Wednesday, June 23, 7:30 pm

Long-term planning for our loved one when we are gone is a topic of epic proportions and concern for many of us. There is no “one size fits all” solution but as I lie awake at 3 am worrying about this dilemma, I know that other family members are doing the same. So, this topic will be the focus of our next 4th Wednesday (June 23) discussion group, 7:30 to 9 pm.

There will be no expert to tell us what to do but this will be a structured discussion about the issues. We hope to develop a list of priority concerns and questions and then find more information to share with each other, either through another meeting, in our newsletter, on our website, or through a speaker presentation.

We won’t have the chance to remind you again about this in our newsletter due to our publication schedule; so save the date and check our website mid-June for Zoom links.

Announcements

- **Case Manager/Care Coordinator available.** We generally do not advertise private services but we know there’s a huge need for case management and consultation help for privately insured and other clients not covered by the county’s Behavioral Health Care Services. **Ryan Gardner** is a LCSW with 15 years of system experience and individuals and family members. He lives locally, despite the title of his website. Check out www.peninsulacounselingandconsulting.com or call him at 650-644-4454.
- **Mental Health Services Act Plan for 2021-22:** To review and submit public comment on the annual plan before May 17, go to acmhsa.org.

(See More Announcements on Page 5)

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SPEAKER NOTES

Strategies for Coping Through Emotionally Challenging Times

Summarized by Thomas T. Thomas

We are all looking for ways of building resilience and maintaining our wellness, especially during these stressful times. **Sarah Carr, LMFT**, is the Founder and Clinical Director of mindfulSF, a Bay Area-based company that offers science-driven mental health services and wellness workshops. Carr is a Licensed Marriage and Family Therapist and a Certified Mindfulness-Based Stress Reduction Teacher. She is trained in Cognitive Behavioral Therapy (CBT), Acceptance and Commitment Therapy (ACT), Mindfulness, and Self-Compassion.

In her clinical work, Sarah Carr specializes in the treatment of obsessive-compulsive disorder and anxiety. She facilitates workshops focused on mindfulness-based strategies for building resilience, supporting well-being, and effectively managing stress and anxiety. More information about Carr and her organization can be found at www.mindfulSF.com.

“I’m interested in making these strategies accessible in everyday life,” Carr said at our March meeting on Zoom. She urged participants to “take whatever is useful in this workshop.”

Our society has a “culture of stress,” she said. In a recent survey, 67% of respondents said they had emotional stress in their lives, 72% showed physical symptoms of stress, and 18% reported clinical levels of anxiety. Meanwhile, 60% to 80% of primary care visits these days involve stress-related conditions.

This situation has only gotten worse during the pandemic. In 2020-21, four in ten people reported anxiety and depression, where in 2019 the rate was just one in ten. And 53% of respondents identified joblessness or financial problems as stressors. This level of anxiety and depression, along with the COVID-19 epidemic itself, is unequally distributed among ethnic minorities and people of color.

And 40% to 70% of caregivers show some symptoms of depression. “Caregiving can be both physically and emotionally stressful,” Carr said.

The strategies being offered at our Zoom meeting might not be sufficient for all issues, she warned, but

they will help build a person’s resilience.

Mindfulness may be defined as “the ability to know what’s happening in your head without getting carried away with it.” It is also “paying attention to the moment without judgment.” It involves being awake and aware, and allowing yourself to explore your own thoughts.

The practice began with Jon Kabat-Zinn at the University of Massachusetts Medical Center in 1979. He is a neuroscientist and Zen Buddhist practitioner who wanted to bring elements of eastern meditation to western medicine. He started with an eight-week program in Mindfulness Based Stress Reduction (MBSR), without the framework of Buddhist beliefs, for people in chronic pain. There he discovered that most of the participants could reduce their use of pain-killers. He later founded the Center for Mindfulness in Medicine, Health Care, and Society at the Medical Center, and authored [*Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness*](#) (1991).

Mindfulness has since grown as a practice and can be used for all sorts of populations, including people with depression, anxiety, post-traumatic stress disorder (PTSD), and physical symptoms. It supports physical and psychological well-being, focuses concentration, improves motivation, productivity, and task-related satisfaction, and produces changes in the brain.

A person’s mind wanders during the day. Carr asked the Zoom participants how much they think their minds wander, and responses were between 15% and 85%. In a Harvard study in 2010 among 2,200 volunteers, the average was 47% of the time. And this is likely to increase with stressors, which heighten distractions and distressing thoughts about the person’s past or future.

Carr then offered two practices that attendees could follow.

The first was a **small movement practice**: the person stands up, closes their eyes or remains half-lidded, and becomes aware of their body, feels their feet on the floor, allows the shoulders to drop, and lowers the chin. Then the person moves their body gently in a circular motion, allowing the mind to wander. They bring their arms over their heads, consciously inhaling and exhaling, then bring their arms down, noticing the sense of motion. They raise their arms again, link their thumbs, and move their body to the right and left.

Then they bring their arms down, letting the body make any other movements.

The second practice was a **seated exercise**. The person finds a posture while seated that is both alert and relaxed. Again the eyes are closed or half-lidded. The person brings awareness to the body, noticing how it contacts the chair or other surface, dropping the shoulders and allowing the arms to feel heavy. They give themselves “permission for a moment or two of space” and acknowledge “anything that’s bothering them, but it doesn’t need to go away.” Again, the person breathes in and out slowly, which helps to slow the mind. As the mind wanders, the person becomes aware of sounds and acknowledges them. The person notices breathing again and slowly opens their eyes.

These practices are similar to the more formal practice of meditation, Carr said.

Being mindful in everyday life can come through the senses: seeing and observing, hearing and listening, smelling and tasting. A person can become mindful of the sensations associated with routine tasks like brushing teeth, taking a shower, or going for a walk.

It’s also useful to find ways to *unplug*—literally separating ourselves from electronic devices and sources of distressing news and outside distractions. “You want to set boundaries around technology,” Carr said. And it’s important to also *fill up*—doing things that are relaxing and satisfying, like gardening, cooking, or taking a walk among the trees. “We are biologically wired to be in nature,” Carr said.¹

She recommended taking “micro-mindful moments” during the day: just pause, check in, and find out what’s happening with you. Other mindful techniques include:

- Taking a timeout when you feel yourself getting fed up, chest tightening, tensing up. Step away, go into another room, find “alone space.”
- Scheduling refuel and buffer time. Decide what fills you up and put it on your calendar like a doctor’s appointment.
- Putting a refuel or buffer step between tasks at work. And leave work items in a separate area.
- Consider factors in and out of your control. Find where you *do* have control and access that space.

Carr also described a 30-second practice called

STOP, which stands for:

- **Stop** for a pause.
- **Take** a breath.
- **Observe** what you are doing, with curiosity, and being open to the experience.
- **Proceed** with what you need in the moment, such as deep breathing or positioning yourself.

Various apps will help with mindfulness, such as [Headspace](#), [Calm](#), and [Insight Timer](#). Books in addition to Kabat-Zinn’s include Dan Harris *et al.*’s [Meditation for Fidgety Skeptics](#). And many websites are available, such as the [Center for Mindful Self-Compassion](#), the [Brown Center for Mindfulness](#), and the [Insight Center](#) in Los Angeles.

The [MindfulSF](#) site also offers eight-week classes that include techniques like the small movement and sitting exercise described here, with an opportunity to discuss their effects with a group of practitioners.

Q. What about those times you take a break, breathe, and encounter painful feelings and grief?

A. You need to hold on to what’s supportive for you and take care of yourself. It is not always good to go inside your head, and it’s sometimes uncomfortable when different feelings come in.

Q. What about our society’s current practice of multi-tasking?

A. That is the total opposite of mindfulness.

Q. A recent article in *Harper’s Magazine* suggested that meditation can have a downside for some of our medically challenged loved ones. For instance, people with PTSD can have flashbacks when they close their eyes.

A. Yes, and focused breath control can be destabilizing for some people. [Willoughby Britton, PhD](#), at Brown University has examined some of these indications in relation to mindfulness and other therapies.

Q. Can we assume that these mindfulness techniques don’t work so well after a couple of glasses of wine or taking other recreational drugs?

A. That’s right. They can cloud the mind, and you want your mind to be clear.

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.thomasthomas.com/NAMI.htm.

¹ See also the Japanese practice of [Shinrin-yoku](#), “forest bathing” or taking in the forest atmosphere.

Musings

[*Hidden Valley Road*](#) by Robert Kolker is an amazing read about a real Colorado family with twelve children, ten of whom become diagnosed with schizophrenia. The story itself is tragic, and for those of us with just one family member with the disease, the idea of magnifying that by ten is incredible. The family story is poignant, and solid attention is given to the family members' coping and frustrated acceptance of the situation. The two unaffected siblings, the only girls in the family, are shown sympathetically as they alter their own life plans.

However, of equal interest, is the systematic inclusion of the "behind the scenes" efforts by the community of psychologists, scientists, and researchers to find the cause and a possible treatment. Alas, the end result is not a "one size fits all" conclusion that X causes Y. Instead, the reader is taken into the research hypotheses and paradigms that inform the struggle to figure out this dreaded disease. It's a fascinating counterpoint to the vivid descriptions of this family's everyday experience of living with schizophrenia. Thanks to NAMI member Jennifer G., who sent me this book.

—Liz Rebensdorf, President, NAMI East Bay

Family Advocacy Update

My own journey with my family member had gone on for seven years and nothing in the system was making sense. But then someone advised me that family members like me had a choice of sinking into resignation or resolving to fight the system and force it to commit to keeping our family members alive and safe. At that point several of us founded [Families Advocating for the Seriously Mentally Ill](#) (FASMI) in about 2018, to continue the work of Voices of Mothers and Others (VOMO).

FASMI has an agenda that is a work in progress, but at the top our agenda always has been the provision of more acute and subacute beds. It is so obvious to us that there are not enough beds. There isn't space for a person in crisis or s/he is discharged too early to make room for someone else.

Many innovations and changes are proposed to help the seriously mentally ill, but so many of these changes do nothing to fix the problem we see. This is why we decided to demand actual, concrete changes

in increasing the number of hospital beds as well as board-and-care beds, and see who can help us find a solution.

This county can be measured and judged by the places it holds its seriously mentally ill. Several hundred of them may be in Santa Rita on any given day, and three thousand or more may be homeless on the street. Others are living at home in shaky circumstances. But only some 300 people with SMI at a time can be in hospital beds, even if they need them desperately, and even if a couple months of treatment would have a good chance of restoring them to some kind of autonomy.

And when our national and state organizations fail to talk about beds, they put off a solution further and further into the future. The "big tent" that embraces all mental illness and substance abuse can get so big that the troublesome 1 or 2 percent that are too sick to demand treatment are left out of the solution.

—Alison Monroe, FASMI

News from NAMI Alameda County: Social Security Benefits in Jeopardy for People with Serious Mental Illness

The current Social Security Commissioner is Andrew Saul, a Trump appointee. From the beginning of his tenure, he has been actively working to gut the Social Security system. For those on disability, he has been implementing rules that are designed to remove people from the rolls. These rule changes are cruel and are causing unnecessary stress for people receiving these benefits.

Many people in our affiliates with have been working successfully on their recovery and are able to work part time. Under the old rules this would have been encouraged.

In January 2021, NAMI Alameda County hired a Connections Recovery support group leader for \$60/month. She reported her earnings to Social Security. Last month she was sent letters threatening to take her off their rolls if she didn't provide employment verification dating back to 1988! She was unable to work for 18 years before being employed by NAMI. Most of that time she was in and out of acute care hospitals, in homeless shelters, or renting rooms in people's house.

NAMI Alameda County and NAMI Santa Clara

are asking people to share how these changes are affecting you or your loved one. The rules for acquiring and maintaining Social Security Disability must be designed to encourage work and recovery rather than punishing people for their illness

—Peggy Rahman, *President,*
NAMI Alameda County

Felton Institute Discussion

At our first 4th Wednesday online discussion group in February, we talked with Jim Christopher and Emily Neapolitan from the Felton Prevention and Early Intervention Institute. (<http://feltonearlypsychosis.org>). Felton's diverse staff sees family members as part of the team that includes a psychiatrist, employment and education specialists, and family and peer support specialists.

Target clientele are Alameda County 15 to 24 year olds on MediCal showing first signs of psychosis. The goal is to provide a short-term intervention to both normalize the experience and prevent the deterioration in other areas of functioning, such as school, work, and socializing. The clinicians use a range of techniques, such as cognitive behavior therapies, motivational interviewing, discussions about medications, and coping strategies with a working theme of "powering with" not "powering over" clients.

Contact jchristopher@felton.org for more information. Thanks to Jim and Emily for joining our discussion. Recording is on our website.

Solutions for Supportive Homes

This organization (<https://www.s4sh.org/about-us>) is seeking families to participate in an LLC partnership to purchase a building in Oakland for our mentally disabled family members that guarantees privacy, community, dignity, permanence, and support.

The Purpose: To provide a life-long home that offers the dignity of a separate living space for each person and maximizes mental health potential in a supportive community-focused residence.

The Property: A nine-unit, each with kitchen and bath, former mansion built in 1911 on a bucolic stretch of Vernon Street in Oakland will soon go on the market. Our Solutions for Supportive Homes

family property group has been assured we have the first rights to buy the \$2.3 million property. The owner's preference is to sell to us.

This is a unique building that would allow privacy for each person within a supported community structure and an on-site 24-hour resident assistant. Solutions that don't address the lack of these actual places do not solve our problem. In coalitions and in national groups we are accused of talking about beds too much. But we have to talk about them, or our coalition partners will just put these beds further and further off into the future. We need more families to join with us to make the purchase financially feasible. There will initially be five units ready for occupation, the remainder will be available as current tenants leave. We estimate the down payment cost to be \$800,000; that is what we need to raise among participating families.

Email linder.allen@s4sh.org or call 650-850-2900.

Announcements (Continued)

- **Family to Family Class** presented by the Family Education Resource Center ([FERC](#)) will be offered starting Thursday, May 13. To register or for more information about this eight-week course, contact lisa@mhaac.org or jisegen@mhaac.org.
- **NAMI National 2021 Convention** will be offered online July 27-28. Registration prices range from \$10 to \$25. The plenary speaker will be the new head of the National Institute of Mental Health. This is a bargain, plus no need for transportation and hotel costs. Information is at www.nami.org.
- **Housing Options:** When Prop 63 passed in 2004, the Mental Health Services Act (MHSA) became a reality. The Alameda County MHSA plan is found at www.acmhsa.org. Scroll down to the section on plan components and check out the Housing Solutions for Health section, which provides a good overview of county-funded housing.
- **Psychiatric Advance Directive (PAD)** is a legal document that states a person's preferences for future mental health treatment and sets up a health proxy to interpret those preferences during a crisis. More information about this state-specific document is at www.nrc-pad.org.



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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

Contact me for Family to Family Education Class

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