
NAMI EAST BAY NEWSLETTER

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

July-August 2021

Telehealth and Changes in Mental Health Care

Wednesday, July 28, 7:30 pm

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.

Dr. Norman will share his experiences with the changing landscape of mental health care and the evolution of therapies, medications, and telehealth over his career, and how the introduction of new technologies like GritX can provide a scalable and personalized approach to helping people when traditional resources are not available.

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 the Unhoused Experience

Wednesday, August 25, 7:30 pm

The topic for our August NAMI night is the Unhoused Experience. Our friend Steven Bucholtz, Program Manager of the Berkeley Drop-in Center, will share his experiences at the center, which serves as a haven for folks who lack housing. Steven describes these folks as "not some monolith" but as a group of individuals with incredible life stories. The transformation of the Center at 3234 Adeline has been amazing to watch, and we will get a chance to meet with and discuss the current housing crisis with folks who are experiencing it.

Go to our website at <https://namiestbay.org> and follow link under What We Offer to register for this online discussion.

NAMI California Annual Conference

This year's conference will be held online October 14 and 15 with the theme of Embracing Change and Transformation. Topics include trends, best practices, new treatments, etc. Register at <https://namica.org>.

Mysteries of Mental Illness on PBS

Mysteries of Mental Illness, airing on PBS in June 2021, explores the story of mental illness in science and society. The four-part series traces the evolution of this complex topic from its earliest days to present times. It explores dramatic attempts across generations to unravel the mysteries of mental illness and gives voice to contemporary Americans across a spectrum of experiences. Catch up with this series at <https://www.pbs.org/show/mysteries-mental-illness/>.

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SPEAKER NOTES

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

Summarized by Thomas T. Thomas

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 idea behind this book,” he said, “is to enable those who assist persons with serious mental illness to better understand rules and laws that are so complex. And to help high-functioning consumers as well.”

Miller said it took him about five years to write the book, but that was just gathering the information, writing, and rewriting. But really, the effort went back thirty years to when his daughter had her first break with reality and he “entered this world” of serious mental illness.

For the first thirteen years of her life, his daughter was bright and cheerful. Then she became antisocial and irrational; she got help from her school and outsiders, who assured Miller this was just a teenage phase. But she slowly deteriorated, and by age fifteen she had wild delusions and hallucinations, was hospitalized, and diagnosed with schizophrenia. “The doctors said the illness fell into three categories: she would stay the same, get better, or get worse. Hers got worse.”

Miller’s response was to become knowledgeable about mental illness and laws relating to it. This became the focus of his legal practice. He also gives advice to other lawyers and to family members without charging or asking for a retainer. “Our burdens lighten when we help someone with similar problems.”

It became apparent to him that it would be useful for other family members and for high-functioning consumers to have a written resource on these laws. The result was this book, which has chapters on:

1. **Communicating with Authorities and Institutions**, including requirements and exceptions for

- incapacity, emergencies, types of authorization.
2. **Hospitalization**, including voluntary and involuntary holds and Lanterman-Petris-Short Act (LPS) conservatorship.
 3. **Arrests and Criminal Justice**, including treatment of mental illness during incarceration.
 4. **Restraining Orders** and the actions needed to obtain one.
 5. **Government Programs and Benefits**, including Social Security Supplemental Security Income (SSI) and Disability Insurance (SSDI).
 6. **Liability of Supporters**, including tort and contractual liability and government reimbursement rights.
 7. **Estate Planning**, with power of attorney, special needs trusts (SNTs), and conservatorships.
 8. **ABLE [Achieving a Better Life Experience] Accounts**, to save money for disability expenses.
 9. **Protecting Assets and Preserving Public Benefits After a Windfall**, including options for giving away or spending down the windfall.
 10. **Authority to Act for a Consumer**, including various types of conservatorship.
 11. **Consumers’ Financial Obligations**, including contracts and how to avoid undue influence and fraud.
 12. **Rights and Obligations Related to Housing and Employment**, including the right to be free of invidious discrimination.
 13. **Strategies for Dealing with Recalcitrant Authorities**, such as giving personal information to induce them to care, showing interest in what they do, informing them of your legal and moral rights, and trying to get third-party help.

Miller said he really cares about the chapter on housing and employment because it clarifies the concept of bigotry for other causes. He also noted that the book, while it cites California law, has wider application: most of the laws and programs regarding persons with mental illness are federal, and California law in this area is generally representative of the laws in other states.

He noted that, while laws and programs for government assistance and protection are valuable, they are often complex and sometimes too much for most of us to understand; so understanding is the purpose of the book. But it is not an exhaustive listing or explanation of all laws and regulations pertaining to persons with mental illness and their supporters. The

book is not intended to replace a social worker or lawyer when required—but it may reduce the number of times such help is needed.

Miller said that, for a parent dealing with someone in authority who may be disinclined to give assistance, the best thing to say may be: “My child needs help. She is innocent, she is vulnerable, and she can’t help herself. So, I am trying to help her.”

He quoted from his Afterword: “Some wise person once remarked that a major difference between those who succeed and those who don’t is persistence. ... When we are caring for a consumer [of mental health services], there is no one in this world displaying a greater mixture of courage and decency than we are. Whether we are acting due to love, or due to a sense of duty, or to a combination of them, we are doing things no rational person would ever voluntarily choose to do if a reasonable alternative existed.”

Q. How active are the laws pertaining to mental illness, and do they change a lot?

Miller said he would like to see changes, which are needed, but he does not expect much to change. But he cited the recent move in Alameda County to “decarcerate” prisoners in Santa Rita Jail being held on mental health issues and recent housing programs.

Generally, however, the electorate and the law views mental illness as “somebody else’s problem.” He said people are now beginning to advocate for change, but he doesn’t know if it will come anytime soon.

Q. What are the chances of the LPS law being modified?

LPS needs modification, but what might change or when, Miller has no idea. “Changes meet resistance and cost money,” he said. “With the economy in such a weird place, it’s hard to be optimistic about change.”

Q. Please discuss fiduciaries and custodial financial accounts.

In planning your estate, you need to establish a trust for your family member with mental illness, and the person who operates it is a fiduciary, handling the money belonging to someone else. Professional trusteeship is usually offered by a bank or other financial institution, but it can be costly. Alternatives are the [Planned Lifetime Assistance Network](#) (PLAN) and the [Proxy Parent Foundation](#). These are non-profit organizations that can offer investment vehicles and personal services. They will charge you, but not as much as a bank for trustee services.

Q. If my dependent is not a trusting person, does Proxy Parent have a way to deal with him?

They can have someone local who has a relationship with the beneficiary work with him. You can also have a sibling or relative who has an interest in the person become a “trust protector” to make sure the fiduciary is acting appropriately. Note that many fiduciaries are trained and licensed in business and accounting, but not in mental health issues. Some are self-educated in this area, but it’s not a requirement.

Q. What means are there to give someone else authority to direct an individual’s psychiatric care?

This is a complicated issue. A person with mental illness can give someone else a power of attorney in both financial and medical affairs, and depending on the wording it would allow you to select a psychiatrist and direct treatment. But the person can readily revoke such power.

When an agent is needed and there is no power of attorney in place, a court proceeding can establish a probate conservatorship, but the beneficiary can refuse it. The only way to compel the person, other than in a criminal case, is with an LPS conservatorship, which can only be sought by the county and places the beneficiary in a locked facility.

Q. How do you talk to the system? How do you express your rights and needs?

The reasons for resistance among people in authority are always varied: There may be no signed authorization in place, or the treatment professionals think talking to you is a waste of time, or they are just having a bad day. You have to find the cause and try to address it. In the meantime, try to maintain control of your emotions, especially when you’re asking politely for something and not getting it.

Q. If my child is resistant to treatment, what about mandatory medication—as opposed to just letting him live on the street?

We really need to change the law in this regard. It’s absurd to allow people with impaired cognitive ability to make treatment decisions for themselves. Libertarian sentiments aside, it should be a right to be taken care of when you can’t take care of yourself.

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.

Musings

When a child falls from the monkey bars (remember those?) at the playground, the caretaker rushes in, comforts, assesses the damage, and applies a bandage and perhaps offers ice cream. When an adult undergoes surgery, illness, or a loss through death, friends and relatives bring casseroles or send Hallmark cards. There are expected ways to respond to a crisis.

Consider, then, what happens when a relative undergoes a fall from reality and has a psychotic episode ... what is the expected response? There is no Hallmark greeting card, and casseroles are not always appropriate. Even the standard “prayers and best wishes” are seldom employed in this situation.

Instead, and this is a familiar situation for many of you readers, you are on your own. This means having to deal with issues involving the police, psychiatric medical personnel, laws and regulations, systemic strengths and weaknesses, and a whole new vocabulary of acronyms and shorthand words such as 5150, HIPAA, ACBHCS, MHSA, 5250, NAMI, etc. It's a steep learning curve, one which is compounded by the emotional distress, challenges, and grief that accompany a crisis. A police presence is fraught with worry and concern about safety issues. And then come the bills for ambulance service, health plan coverage, and ongoing care strategies. Whereas an individual can be most competent in other areas of functioning, suddenly that sense of control over one's life is whisked away, and the sense of powerlessness and lack of agency dominate.

It is in this state of crisis disarray that family members are called upon to deal with the behavioral health system, which has good intentions but limited funds and a massive set of rules and regulations, along with political undercurrents. Often the family's first contact is with a psychiatric nurse at the psych emergency ward. As they assess your ill relative, the psychiatric staff often interacts with generally sleep-deprived, anxious, stressed out, and grieving parents who are questioning the decision to call the authorities, worrying about the next step, and wondering what happened to their child ... and will they get through this? This is not always an encouraging introduction to the support needs being envisioned by hospital staff as they assess your loved one.

Too many of us share this devastating life

experience and we need each other—we need to talk with others who can empathize and understand our panic. You are not alone ... take care of yourself.

—Liz Rebensdorf, President, NAMI East Bay

Resources

The Mental Health Association of Alameda County, with an office located in North Oakland, contracts with the Alameda County Behavioral Health Care System (ACBHCS) to provide several family-friendly services. Their website, www.mhaac.org, offers a comprehensive overview of these services. One feature of note is the Family Caregiver Quick Guide, located on the Family Caregiver Advocacy Specialist page. The association's services include:

- **Family Caregiver Advocacy Specialist:** Bev Bergman. Hours 11:30-7:30 Monday through Thursday, 9-5 Friday. Cell 510-393-9275, Office 510-835-5010.
 - **Family Education Resource Center:** <https://ferc.org>, 888-896-3372.
 - **Patients' Rights Advocates:** 800-734-2504. See the website page for a good explanation of issues they handle.
 - **Grievances:** 800-779-0787
 - **Family Partnership:** 510-383-5129, for families of children and youth who are clients of ACBHCS.
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Care First, Jails Last

The "Care First, Jails Last" resolution passed, unanimously, at the meeting of the Alameda County Board of Supervisors on May 25. It was a tough sell, requiring lobbying and testimonials from family members, Families Advocating for the Seriously Mentally Ill (FASMI), NAMI Family/Caregiver support leaders, providers, advocates from Decarcerate Alameda County, religious leaders, and community members. Our supervisors listened as we told our stories of the trauma that people with mental illness incur when they become involved in Alameda County's criminal justice system.

The resolution calls for a just and equitable transformation of criminal justice, behavioral health, and wraparound services that reduces the number of people with mental illness, substance use, and co-occurring disorders in Santa Rita Jail.

The “Care First” resolution would implement the goals of the Justice Involved Mental Health (JIMH) Task Force, which is set to conclude its work on June 30, 2021, proposing strategies to divert the mentally ill from entering the justice system. A Brown Act committee of 25 people representing stakeholders will be formed and will include community members, care providers, and nine representatives from our criminal justice system. It’s important to have a family member of the SMI on the board because no one else can represent the interests of the truly seriously mentally ill with anosognosia. Since these clients can’t lobby or advocate or petition on their own behalf, they can get left out at every step of every process and fall through every crack. Membership on this committee will need an appointment from your district’s supervisor. Let us know if you’re interested.

All too frequently people are put into jail for displaying symptoms of serious mental illness. This is confusing and painful for them, particularly during the first break. The harm of this experience endangers prospects for recovery. While this mistreatment is common for individuals of all ethnic groups in Alameda County, African Americans are four times more impacted than Euro Americans.

The Department of Justice apparently plans to file a lawsuit against Alameda County claiming that the use of Santa Rita Jail, John George Psychiatric Hospital, and acute care facilities violates the U. S. Constitution and the Americans with Disability Act. The Alameda County Board of Supervisors is motivated to take action to avoid a costly lawsuit. But it matters a lot to us family members what actions the supervisors choose to take, so we need to stay involved in the process. The board needs to understand serious mental illness as we do, and understand that the continuum of care requires hospital beds and supportive housing.

Jail must not remain an integral part of Alameda County’s treatment system. People must not be punished because their brains do not function properly.

The “Care First, Jails Last” resolution is one small step towards a mental health system that is based on need rather than the “fail first” system we have now, where people must be imprisoned for some offense, or cycle over and over again through

emergency care, before they get the attention of the system.

—Peggy Rahman, President,
NAMI Alameda County
—Alison Monroe, FASMI

Recap of the Online Discussion at the Bay Area Hearing Voices Network

The Bay Area Hearing Voices Network is a non-profit 501(c)(3) organization that seeks to expand public awareness, provide community support, and provide refuge for those who hear voices, see visions, and experience other forms of extraordinary perception. For more information, visit the website www.bayareahearingvoices.org.

At our April online discussion group, Ed Herzog from BAHVN described the organization, its schedule of peer and family support groups, and discussed the underlying premise of the movement

A new offering, an on-line weekly night of fun and games, is the BAHVN Game Night, Thursdays 5-7 pm. Game play is free of charge to BAHVN adults, TAY, and family members. All attendees are required to open an account at boardgamearena.com, where the game night will be held online. Go to the BAHVN homepage for a Zoom audio link to Game Night.

SB 221 Passes California Senate

SB 221, the bill to close a loophole that has forced Californians to wait weeks or months for follow-up mental health care appointments, sailed through the State Senate on June and is heading to the State Assembly. We encourage advocacy efforts on the bill’s behalf in the Assembly.

The bill would require HMOs and insurance companies to provide returning appointments for mental health and substance use disorder within ten business days, unless a mental health therapist determines that a longer wait would not be detrimental to the patient’s health. The bill would do this by closing a loophole that requires patients to receive an initial mental health therapy appointment within ten business days, but does not provide the same mandate for follow-up appointments.



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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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