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# NAMI EAST BAY NEWSLETTER

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

March-April 2022

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## Mental Health Law: A Road Full of Potholes and Roadblocks

Wednesday, March 23, 7:30 pm

**Paula Aiello** is a Bay Area native who comes to us as a family member, educator, activist, and attorney. She is on the steering committee of Families Advocating for the Seriously Mentally Ill (FASMI) and originally gave this presentation to that group. Her talk covers the history of mental health laws and regulations from a global, national, state, and local perspective and offers a valuable framework with which to view our present conundrum.

You will find her presentation highly informative as she discusses the origins, status, and problems of the myriad of laws which govern public provision of services for the mentally ill.

### Speaker Meeting starts at 7:30 pm

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

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## 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://namiastbay.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.

## In Memory of Vivian Jackson

We are saddened to share the news that our founder, Vivian Jackson, died in December at the age of 99 years. She was a force of energy, wisdom, humor, and kindness throughout. Originally the president of an American Schizophrenia Foundation group, she gamely led us through the rigmarole of becoming a NAMI affiliate in 1981, with the eventual move to our present space in Albany. Many of us old-timers remember meeting each other at the support groups she ran and enjoying her perspective and downhome use of language. As she aged and left the organization, we got together and continued to enjoy her wisdom and generosity. Let us know if you'd like to be informed of memorial services.

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## In Appreciation of Our Donors

We want to thank those who have generously contributed funds to NAMI East Bay. Such donations are what finance our office space, utility bills, and the several technical services (Zoom, MailChimp, and website processing and maintenance services) we've been relying on these last few years. In particular, we'd like to acknowledge the donation made by several readers in honor of Vivian Jackson (see above) and by Terry Pink Alexander in memory of Dr. Jamie Edmund.

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## Parent and Peer Support Specialist Certification

Senate Bill 803 was passed in September 2020 to certify those with lived experience as support specialists. Areas of family representation and core competencies are currently being discussed by Alameda County's offices of Family and Peer Empowerment. Certification Stakeholder meetings are being held monthly; contact [Khatera.Aslami@acgov.org](mailto:Khatera.Aslami@acgov.org) for information.

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### SPEAKER NOTES

# Our Pandemic Perspective in January 2022

*Summarized by Thomas T. Thomas*

We are all unwilling participants in this historic pandemic. Heading into January of the third year, it was time to take stock and share our perspective of where families of individuals with mental illness have been, where we're going, and what lies ahead.

NAMI East Bay President **Liz Rebensdorf**, a former school psychologist and now a leader of support groups, called together a round-table discussion by five providers with direct access to and knowledge of the situation on the front lines. Here is their report.

"Families are first responders to people with mental illness," Rebensdorf said. These women have experience, either professionally or as a volunteer, with families dealing with mental illness. She asked them to share, first, observations from the past year or so and how people are coping with the pandemic's effects, and then share something positive.

**Beverly Bergman** is a Family Caregiver Advocacy Specialist with the Mental Health Association of Alameda County who works out of the lobby of the John George Pavilion when it is not locked down due to Covid-19. She also has a daughter with bipolar disease and dual diagnosis.

"It isn't easy to get mental health treatment in the county these days," she said. "People, even those in full-service partnerships, just don't show up for appointments." She used to help people get benefits and now she just tries to help families. She also noted that it's more difficult to get police to execute a 5150, because they are now reluctant to put their hands on other people.

**Patty Espeseth** is Chief Administrative Officer of the Alameda Health System, in charge of intake at John George, and also is a support group leader with Alameda County NAMI. She calls family caregivers "unpaid social workers" and "the people who get it." She said it was easier to be a provider these days than a family caregiver.

Although the Omicron variant is less deadly, she said that deaths are still occurring. And the testing is not helping, because people come into the hospital for

other issues, receive a positive test with no symptoms, and must be quarantined. People with mental health issues usually have nowhere else to go and can't be moved, and so the hospitals become "Covid hotels."

The staff have set up special zones in the hospital: red for people with the disease, yellow for those under investigation, and green for people without Covid. "All of this is hard on folks and the staff," she said.

**Rebecca Woolis** is a family therapist and author of [\*When Someone You Love Has a Mental Illness\*](#). She had long experience with public mental health programs and case management in Marin County, San Jose, and at Berkeley's Bonita House and the Creative Living Center before she semi-retired into private practice.

"For people with mental health issues," she said, "the pandemic has exacerbated symptoms like paranoia and obsessive-compulsive reactions." With the isolation, there are less available services and people are afraid of getting sick. People with dual diagnosis are also more prone to relapse.

For providers of mental health services, especially access teams in the community, isolation, anger, and anxiety are creating physical problems and difficulty sleeping. "Frustration, isolation, and fear affect all of us, including family members," Woolis said. "Relationships are stressed."

**Katy Polony** is a Family Advocate on one of four In-Home Outreach Teams (IHOTs) in the county and a co-founder of Families Advocating for the Seriously Mentally Ill (FASMI).

Polony said she took the IHOT position in order to acquaint herself with the system for the benefit of her mentally ill son. "IHOT teams in the county connect people to services they do not want," she said.

About half the people IHOT reaches are in families, and half are on the streets—and both groups go in and out of jail. IHOT has a family advocate to collaborate with family caregivers. On the streets, mentally ill people acquire methamphetamine and fentanyl habits, Polony said.

"The families who call the IHOT are desperate and frightened," she said. "And it's become more difficult to get their loved one hospitalized." Police want to de-escalate rather than enforce a 5150. They tell parents to get a restraining order, which turns the situation into a criminal matter, and then the police are forced to take the family member into custody.

FASMI is fighting the dysfunction in the system. Their goals, Polony said, are more beds, more housing, and more full-service partnerships.

**Kate Kosmos** is a School Psychologist with the Oakland Public School District. She works as a therapist, trains school staff, and is on the faculty of Holy Names University.

The trend in schools these days is exhaustion and “pandemic fatigue,” and the workforce to support students is stressed. Professionals are seeing more truancy, more substance abuse, more psychiatric hospitalizations. There is a higher referral to special ed classes in kindergarten and first grade for behavior issues, because these students have missed thirteen months of personal development at a crucial time in their lives.

**Liz Rebensdorf** said support group members reported more anxiety and depression, more isolation, more resort to device use, and more edginess. Families were experiencing interpersonal problems due to the pandemic, climate change, and politics.

Family members with schizophrenia, hypervigilance, and body dysmorphia were reacting especially badly to the pandemic. “It’s not nuanced,” she said.

Then, as to positive trends and observations, **Beverly Bergman** reported that her daughter, after several relapses, has been sober now for six months.

**Patty Espeseth** said the pandemic had been a “great equalizer,” that people were all in the same boat, and she was seeing them be “a little kinder” to each other. As someone in inpatient treatment, she was happy to see people get better on medication.

She said there was a lot of pride among the staff of her “safety-net hospital,” because they were “working at a place that takes care of everybody.”

**Rebecca Woolis** noted that the isolation of the pandemic and people keeping social distance was actually a relief to people with social anxiety.

Woolis said there was now more general awareness about mental health needs and the lack of services. She also noted that people were bonding as a community and using technology to connect with friends and family who were far away. Telehealth was also becoming more accepted, including for mental health services.

**Katy Polony** said that when the pandemic hit, it almost crushed them: the caseload increased while the number of practitioners decreased. They got through, though, and the pride and camaraderie—the sense that

they were doing the best they could and keeping people alive—was bringing the team together.

She noted that FASMI has also helped her turn anger at a dysfunctional system into being able to accomplish something good. The group is spurring people to advocacy—and she announced a February 13 sleep-in on the county Board of Supervisors’ steps.

**Kate Kosmos** described “amazing things” happening in the Oakland schools, including the breakfast and lunch programs that continued feeding thousands of children, not just students, because for some it was their only meal of the day.

Kosmos was seeing people reach out and check in, with technology enabling their conversations. During the toilet paper and other shortages, she saw people switching supplies between households. She also saw more families doing art together; they were channeling their emotions into creative expression.

She also saw people out walking in the evening, after the period of lockdowns, having the resilience to grow from hard experience.

**Liz Rebensdorf** described what people in the support groups were doing for themselves: getting out among nature, getting more exercise, and exploring webinars and online docent tours. She said that one group had started a weekly dance session on Zoom. People were stretching out of their comfort zones, she said.

Rebensdorf also described some recent state legislative moves that would help with mental health issues during the crisis.

[Senate Bill 224](#) would provide for age-appropriate mental health awareness in education.

[Assembly Bill 988](#) would provide special crisis hotline centers for suicide prevention.

And a new program, [CalAIM](#), would seek to improve MediCal services with whole-person approaches to care, improved quality outcomes, and seamless navigation for MediCal enrollees.

In closing, Rebensdorf described a contact she had with a tech-support service person working from home. When asked, the woman said her four children studying at home were becoming closer, and that was a positive thing.

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](http://www.thomasthomas.com/NAMI.htm).

### Musings

Two things to muse about in this edition:

**CHANGE**—These last two years have demanded so much of us in terms of coping. Of particular import seems to be the need to be flexible, to deal with transitions and embrace the necessity of going forward with Plan A—and B—and C. ... So it is with the NAMI East Bay affiliate.

We've coped these last two years with trying to offer services to families within a different format, avoiding face-to-face contact but spending a lot of time on Zoom and other online platforms. Who knows what lies ahead? At these crossroads, we invite your input and participation as we think about how to make a positive transition into the "moving forward" stage.

Among the changes will be one of leadership, and our Board of Directors is considering several possibilities of making shifts while maintaining services. Here's where we are inviting our members and readers to consider joining our board or becoming a member of an advisory committee.

Our board of genial folks meets once a month (currently online) with periodic retreats, holiday gatherings, and online communication. An advisory committee will probably take on a more task-specific role. All applicants will be given an overview and introduction to the workings of the affiliate. Do let us know if you're interested.

**CONFIDENTIALITY**—Having recently been given the opportunity to address the psychiatry staff at a local mental health provider, I want to share one of the topics I stressed to this group. The 1996 Health Insurance Portability and Accountability Act (HIPAA) regulations on confidentiality inform one of the problems that many families have when their ill relative is receiving services.

First, as family members we consider ourselves part of the treatment team and want to reinforce goals that are laid out by the clinician. Too often, our relative is asked only once if s/he will sign a Release of Information (ROI). We ask clinicians to revisit that request on a regular basis, since with treatment, hopefully, the perspective of our relative will soften.

Second, we tell families that they can leave phone messages or emails for clinicians to alert the professionals about incidents, issues, etc. We prepare families to not expect a response or chat because of

HIPAA, but families are often distraught upon learning that the clinician shared that information with the client, and often family relationships are damaged, sometimes irrevocably. There is no regulation saying that the clinician needs to share such private information with the client. Clinicians need to explore other ways to open up a topic.

Remember to stress these requests when you next deal with a service provider.

—Liz Rebensdorf, President, NAMI East Bay

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### FASMI Protest Rally February 13-14

The Families Advocating for the Seriously Mentally Ill (FASMI) group and other concerned family members and citizens held a protest rally and sleep-in February 13 and 14 at the site of the offices of the Alameda County Board of Supervisors (BOS).



The primary demands, which the group wanted addressed by the BOS, are for more hospital beds, for more licensed permanent supportive housing, and for an unbroken continuum of care for those with SMI. The group asks for assertive county action to secure some of the billions of dollars that are state designated for these services and to build up the mental health systems at sites other than the county jail.

At this writing, it remains to be seen how the Board of Supervisors will process the issues, but the feeling in FASMI is positive, and there was good press coverage of the family perspective. The collective positive energy and skills of group members produced a smooth, creative, and effective event.

In putting the issues of our mentally ill relatives into the context of the grieving, loving, but helpless families they belong to, it seems the humanizing process can begin. Our relatives cannot advocate for themselves, but families can mobilize and harness their persuasive and political clout. To contact FASMI, email [acfasmi@gmail.com](mailto:acfasmi@gmail.com).

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### Wellness Centers and Hubs in the East Bay

The Wellness Centers and Hubs offered by Bonita House and Bay Area Community Services (BACS) are wonderful community resources available to all those with a mental illness and serve as an “entry point to recovery and supportive services for those with a broad range of mental health needs.”

Activities vary but may include group discussions (general and topic-specific), games, and art experiences. Services and hours vary at the sites and accommodations to those services have had to be modified because of Covid, but they are truly worth exploring.

Bonita House ([bonitahouse.org](http://bonitahouse.org)) offers two centers: Casa Ubuntu at the Eastmont Mall, 510-735-0864, and Berkeley Wellness Center, 510-809-3004.

BACS ([bayareacs.org](http://bayareacs.org)) offers Towne House in Oakland, 510-658-9480; Hedco in Hayward, 510-247-8235; South County in Fremont, 510-657-7425; and Valley in Pleasanton, 925-484-8457.

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### Mental Health Association of Alameda County Has a New Website

We invite you to go to <https://MHAAC.org>, the brand-new website for the Mental Health Association of Alameda County. There you will find solid information about their programs like Patients’ Rights, Family Partnerships, Consumer Complaints, and the Family Education and Resource Center (FERC). The embedded FERC website (<https://mhaac.org/mental-health-services/ferc>) is a comprehensive source of information about hospitalization, incarceration, and medications. Check it out.

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### Covid and Mortality Among the Seriously Mentally Ill

There have been urgent and ongoing studies of the risk that individuals with severe mental illness face.

Last August, a meta-analysis of 16 studies in seven countries found a mortality rate 1.67 times that of average in patients with SMI and Covid. Questions were raised then about social conditions including access to care, socioeconomic status, and the presence of comorbidities associated with severe mental illness.

A more recent study referenced in the Treatment Advocacy Center’s [Research Weekly](#) for January 12, 2022, examined electronic health records of than 2.5 million individuals in the US. After controlling for demographic variables and comorbid conditions, the study found that people with schizophrenia were four times more likely to die from Covid-19 compared to the general population.

“People with severe mental illness experienced some of the worst mortality disparities pre-pandemic, and are some of the most vulnerable Americans, with a life expectancy up to 25 years lower than the general population. Disparities based on mental illness are often magnified by disparities related to poverty, race, or other factors that create barriers to timely health care. New data suggests that many people with severe mental illness will die from preventable COVID-19 infection unless swift action is taken.”

This fact drove the placement of people with SMI onto the local priority lists for vaccines. We can only hope that it also drives some medically curious researcher to explore this specific connection in hope of furthering our knowledge.

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### Suicide Prevention and Mental Health Awareness Walk

The UC Berkeley suicide prevention club [You Mean More](#) is partnering with the American Foundation for Suicide Prevention (AFSP) to hold a walk on Saturday, April 9, 2022, from 10 am to 1 pm.

More information can be found at <https://supporting.afsp.org>, or contact our office by email for the complete, four-line website link.

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Please check your mailing label. If the code "22" is over your name on the right side of the label, your dues are current through 2022. If your mailing label indicates a previous year, or nothing at all, your dues are not current.

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

Make checks payable to "NAMI EAST BAY" and mail to NAMI East Bay, 980 Stannage Avenue, Albany, California 94706

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