
NAMI EAST BAY NEWSLETTER

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

May-June 2019

How Technology Can Help Psychiatry Improve Patient Outcomes Wednesday, May 22

Dr. Kim P. Norman, MD, is a professor at the University of California San Francisco¹ and a psychiatrist with over 40 years of experience caring for teens and young adults with complex behavioral health issues. In 2004, Dr. Norman founded the Young Adult and Family Center (YAFC) at UCSF, dedicated to creating and disseminating innovative mental health services, including digital health services for adolescents, young adults, and their families. The YAFC aspires to build a center of national prominence where troubled young people and their families receive the best available clinical care, irrespective of their ability to pay.

Our bimonthly general meeting is held in the social hall of the Albany Methodist Church, 980 Stannage Avenue, Albany, 7:30-9 pm. Admission is free and the public is welcome.

Speaker Meeting starts at 7:30 pm

Albany United Methodist Church
980 Stannage Avenue, Albany
Corner of Stannage and Marin

Meeting is free and open to the public.

Support Meetings

NAMI East Bay offers the following monthly support meetings:

- **Support and Share Group for Families of Adults** is held on the 2nd Wednesday of each month. The next meetings May 8, June 12, and July 10.
- **Support and Share Group for Families of Children, Adolescents, and Young Adults** is held on

the 3rd Tuesday of the month: May 21, June 18, and July 16.

Support Group Meetings are held at the Albany United Methodist Church, 7-9 pm. Enter through the gates to the right of the door on Stannage Avenue, turn left through the large room, go down the hall, and come up the stairs. Signs will be posted.

All support meetings are free to NAMI members and non-members, offering a chance to talk with others who understand, give emotional support, and share ways they have found to cope.

Chinese American Mental Health Awareness Day

Saturday, June 1, 10 am-3pm

**Multipurpose Room, East Bay Campus of CSU
25800 Carlos Bee Boulevard, Hayward**

This event will include a documentary film, lunch, music, and an inspirational speaker. Mandarin Chinese will be used. Parking is free. Online registration is at <https://mhaac0601.eventbrite.com>. Contact Elaine Peng at ep@namichinese.org or 510-362-1456.

Support Groups

NAMI East Bay offers two monthly family support groups: see nearby on this page or on our website about our groups for families of adults and for families of youth and young adults.

Other support groups are available nearby as well:

- A second Wednesday group meets at Kaiser in Richmond, 6:30-8 pm, 901 Nevin Avenue, Room 317, Conference Room 1, with Dr. Sumchai, 510-237-9277.
- The African-American Support Group meets on the fourth Tuesdays, 5:30-7:30 pm, at the Mental Health Association, 954 60th Street, Oakland.

¹ UCSF Distinguished Professor of Adolescent and Young Adult Health; UCSF Weill Institute for Neurosciences; Director, UCSF Young Adult and Family Center.

SPEAKER NOTES

When the Caregiver Can No Longer Provide Care

Summarized by Thomas T. Thomas

One of the greatest challenges that trustees of special needs trusts face when providing for a beneficiary with mental illness is the lack of appropriate case management services. **Stephen Dale** discussed how to create a special needs trust that incorporates case management for the beneficiary in order to ensure the best possible quality of life. **Christine Grabowski** will discuss the advantages of coordination between the trustee and [East Bay Innovations](#) (EBI) Case Management Services.

Stephen Dale is an attorney who focuses on special needs trusts and is the trustee of the [Golden State Pooled Trust](#) (GSPT). His interest in mental health began early in his life, because his family worked for three generations in California's state hospitals. He himself worked for 17 years as a psychiatric technician, later becoming a civil rights attorney, and eventually focusing entirely on estate planning for persons with disabilities, with a major focus on special needs trusts.

When the hospitals were shut down in the 1960s, Dale said, the intention was to move patients into the community, where they would be served by programs and halfway houses—but none of those services were adequately funded and none are left. “A return to the hospitals just won't work in today's world,” he said, “but neither does community treatment and the promise of making these patients part of the community with no programs.”

He pointed out that special needs trusts (SNTs), which provide for a beneficiary's care, don't generally work when a sibling or family member is named as the trustee, especially in cases where the beneficiary has mental health issues. The better course is to hire a professional fiduciary to manage the trust and have a family member as “trust protector,” overseeing the fiduciary. But neither family members nor fiduciaries are experts in the local programs and resources needed to provide quality of life for a person with mental illness.

What EBI and GSPT propose is a new combination of services: both fiduciary and case manage-

ment, to provide quality care from existing programs and community agencies with the resources you have in a changing environment.

Dale and Grabowski are looking for support in their quest to spread this model as a better way to serve SNTs outside of Alameda County and across California. They call this program the “Life Passage Planning Project.” It is a non-profit effort funded by the May and Stanley Smith Trust and Poses Family Foundation and overseen by Stetson University's College of Law.

Although East Bay Innovations is working with Golden State Pooled Trust on this project, they are available to work with other SNTs and programs.

Christine Grabowski is Director of the Life Planning Program with EBI, which has been offering case management services for 25 years, mostly for people with intellectual and developmental disabilities (IDD). She started out as an Independent Living Skills instructor in 2008. She began working part-time as an instructor in independent living services, and over the course of three years worked her way through several positions, including Assistant Director of Independent Living Services and Director of Supportive Living Services. In November, she entered her new role providing case management and advocacy support.

EBI currently serves about 250 people in Alameda and Contra Costa counties, most of them with developmental disabilities who are served by the Regional Centers of the California Department of Developmental Services.² EBI is already delivering services to about 50 people with mental health issues.

The organization has a “person-centered” approach, forming a long-term relationship with the beneficiary in order to understand his or her needs. Although EBI has no control over funds in the special needs trust and does not authorize spending, they can provide benefits management, including Medical and Medicare, Supplemental Security Income (SSI), State Disability Insurance (SDI), and manage housing support; supported living services (SLS); and in-home support (IHS). They also help plan for independent living, including training for budgeting, shopping, nutrition, and meal planning.

² Patients with mental illness do not qualify for Regional Center programs.

EBI is not itself a caretaker organization but will work with local caretakers and agencies. Dale pointed out that most professional care managers, social workers, and registered nurses have more experience with seniors and their needs than with the mentally ill. Grabowski admitted that EBI is new to working with fiduciaries and SNTs, and its services are currently more aligned with independent living than with supported living situations.

The program's services are offered through a three-step process:

1. Assessment of the beneficiary's needs, including an assessment form, interviews, and a background check in support of housing requirements.
2. Creation of a delivery plan based on those assessed needs.
3. Periodic re-evaluation and modification of the delivery plan.

EBI's case managers will maximize the use of publicly funded services and generic resources; locate affordable housing; access health care and assist clients in following treatment plans, including taking them to appointments; advocate for and maintain public benefits; assist with recruiting, hiring, and training in-home workers but not hire them directly; address safety at home and in the community; promote activities and opportunities for enhancing quality of life; and maintain case records and document expenditures for monthly reports to fiduciaries.

The last point about documenting expenditures is important, Dale said, because Social Security intends to review every expense made by the beneficiary. EBI can teach participants in independent living how to keep track of their receipts.

"We want the beneficiary to be as independent as possible," Grabowski said, "and we will go all-in to teach them the skills they need."

At the same time, EBI's goal is to extend the life of the trust. As part of the re-evaluation process, they will phase out services as needed to achieve this.

Q. How much should you put into a special needs trust? And what happens when the funds are used up?

The funding depends on the age and situation of the beneficiary, so there is no rule. Many bank trust departments expect to manage amounts of \$250,000 and up. When the funds run out, services end, but EBI is conscious of costs, seeking the best quality of

service for the lowest cost. And as funds begin to run out, they can focus on vocational training.

Q. What do these services cost?

An attorney may charge \$1,500 to \$2,500 to draw up a special needs trust. A professional fiduciary trustee may charge 1.5% of trust assets or about \$1,500 per year. Beneficiary case management can cost about \$180 per hour, but EBI seeks programs that can easily adapt to deliver these services and can usually find better quality at a lower rate.

Dale warned against thinking of the SNT as a "magic document." The trust is only as good as the people administering it, and you are buying their experience in dealing with the mentally ill and in case management.

Q. Does EBI have the resources needed to deal with mental health issues?

The program has staff with degrees in both psychology and social work, as well as registered nurses. Most are in training for advanced degrees. Everyone in the program gets training in mental health issues, benefits, and substance abuse. Some have experience with homelessness. However, based on the personal assessment, they won't work with patients who present a serious safety issue.

Q. If the beneficiary dies early, is money left in the trust be collected by SSI? And if the beneficiary is found at fault in an accident, is the trust money forfeited?

No, the trust money is protected. At the end of the beneficiary's life or need, the amount left goes wherever the trust document directs it.

Q. Can the attorney who draws up the SNT become the trustee?

Some do. Golden State Pooled Trusts doesn't, because that has the appearance of self-serving.

Q. Do I have to be part of GSPT to get case management services from East Bay Innovations?

EBI can work with other pooled trusts or private fiduciaries, based on individual assessment. The SNT does not need any special language to delegate duties to an agency like EBI.

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

Musings

A friend gave me a book titled *Mental Illness: A Guide for the Family*, written in 1942 by Edith Stern. I took a look at it and was prepared to make snarky comments about the misguided way our society handled mental illness 75 years ago. *Au contraire* ... it was an eye-opener of how things were in our parents' day when there were no psychiatric medications but plenty of "mental hospitals." Decades later, stories developed about the abuse and warehousing that occurred in these institutions and so they were shuttered and communities were told to take up the slack. Now, this is not meant to be a diatribe against that political decision, but do drive past the many homeless encampments that populate the Bay Area and reflect on how that all worked out.

Back to the book ... I want to share, verbatim, some of what I found and mention at the same time that this is a kind book showing lots of compassion for our folks with mental illness. Hospitalization is a main focus of the book, since apparently it was the only show in town, and much is made of choosing between private and public sites. On preparing to take one's relative to the mental hospital, "Do not lie to him. Even force is preferable to deception ... (the patient will) have little confidence in you and the hospital into which he has been tricked ... take your relative in the daytime when more of the hospital's personnel are on duty ... take along necessities for the first few days which the patient will spend in bed."

The necessity list includes two pairs of pajamas, bathrobe—no cord, bedroom slippers, comb, brush, toothbrush, toothpaste, and for women, face powder and rouge—in cake form. Also, send along a few books, magazines, and trinkets. Keeping patients in bed for the first couple of days was advised for several purposes: a comforting sense of place while healing; nothing to do but lie quietly and be waited on; availability for staff observation and evaluation. Once the in-bed days are over, those who are "more difficult" exercise in the gymnasium "or are given simple activities such as rolling balls or unraveling burlap."

The hospital-offered treatments are listed as shock therapy, fever therapy, prolonged sleep therapy, psychotherapy, psychoanalysis, hypnosis, physi-

otherapy, hydrotherapy, re-education, occupational therapy, physical training, and bibliotherapy. "Don't assume your relative will be neglected if you do not tip hospital employees."

Overall, the author's description of daily life at the mental hospital includes warm individualized staff support and a smorgasbord of activities: social, arts and crafts, physical, occupational, etc. Hospital stays are noted as lasting from weeks to months to years. The process of leaving the hospital is a long one with the word "paroled" standing in for "discharged."

Throughout this book, I see no mention of medications other than sedatives, no insurance plans, no dual diagnosis or use of street drugs, no patients' rights, no confidentiality issues, no homelessness or housing issues—to name a few of the elements we consider today. Things have certainly changed, and are we any better off today in terms of addressing the issues around mental illness? In 75 years—say, in 2094—will they look back on society's current endeavors at dealing with mental illness and judge us as well-meaning but terribly naïve and ignorant?

While on the subject of books, you might want to pick up Esme Wang's new book titled *The Collected Schizophrenias*. While she has a perspective we may not all share, her writing is poignant and authentic, and she presents a picture of the current state of society's treatment of the mentally ill.

There is a possibility of developing a book discussion group, if there is interest. (Although it is difficult to multitask by reading and unraveling burlap simultaneously ...)

—Liz Rebensdorf, President, NAMI East Bay

Update on NAMI at UC Berkeley

We're pleased to share the happenings at our adopted NAMI on Campus affiliate:

NAMI at UC Berkeley is launching a student-led lobbying campaign to establish statewide standards of training and protocol for emergency room staff when dealing with patients with mental and behavioral health issues—specifically in symptom recognition, non-violent crisis intervention, and moderating the use of traumatic methods of control such as physical restraints, seclusion, and sedation. Our members will be writing editorials, gathering and analyzing

data, and traveling to meet with various California representatives to discuss and collaborate on a bill to propose for the 2020 legislative session in Sacramento.

In order to make this endeavor as effective and efficient as possible, we are looking for potential allies to share their experience with mental health crises in the ER, connect us with political allies and resources, and—for those living in districts within two hours of Berkeley—act as hosts so that we can save money on hotel rooms. If you are willing to provide any of the above, please write to nami-ucb@gmail.com or call External Vice President Liz Gobbo at 541-380-1321.

On another note, NAMI at UCB recently published *TAKECARE*, our Spring 2019 'zine (miniature DIY “magazine” of art and writing) on healing, self-care, and mental health. You can access it for free at https://issuu.com/ucbnami/docs/take_care. We hope you and your loved ones will enjoy it, find strength in its message, and even submit to our next issue in the upcoming fall or spring semesters! Open to students and community members of all ages.

Hearing Voices Workshop

An introduction to the Hearing Voices Movement: Voices, Visions, Special Messages, and Unusual Experiences

Do you experience voices, visions, special messages, unusual beliefs, or extreme states of consciousness? Do you love or work with someone who has any of these experiences, and do you want to build understanding and/or be a better support? If so, then please join us for this one-day workshop that will include an overview of the Hearing Voices Movement, personal stories, strategies, and more!

Saturday, May 18, 10am-5 pm
South Berkeley Senior Center
2939 Ellis Street, Berkeley

The cost is \$45 for family members, clinicians, and caregivers. Free for those with lived experience. Lunch is included! The trainers will be:

- **Caroline Mazel-Carlton**, Director of Training for the Western Mass Recovery Learning Com-

munity, and a nationally recognized speaker who keynoted the 2018 Hearing Voices Congress in the Hague, Netherlands.

- **Cindy Marty Hadge**, Lead Trainer for the Western Mass Recovery Learning Community, and a nationally recognized speaker and trainer.

WRAP Training

The Wellness Recovery Action Plan (WRAP) is a well-regarded process that helps individuals with mental illness take concrete steps in dealing with recovery. PEERS is the active consumer organization that offers these trainings.

Once a month, on a selected Thursday, they offer a One-Day WRAP training program, as well as an open WRAP session on Fridays. WRAP is offered at their Oakland (Hegenberger Road) conference room as well as in the community at schools, churches, and other centers. Check out their comprehensive website at www.peersnet.org for more information.

Thank You to Our NAMI East Bay Volunteers

If you are reading this in hard copy, you want to thank Mary Blume, Marilyn Wong, Ariel Herzog, Sally Pugh, and board members who sat around one afternoon talking, nibbling snacks, watching TV's C-Span news ... and sticking round labels and address labels on the newsletters.

Thank Carla Wilson for delivering the labeled newsletters to and negotiating the mailing process with the U.S. Post Office (in between professionally playing her bassoon).

Thank Michael Godoy who sent the newsletter out electronically (in between developing a statewide interactive mental health online service).

And thank Tom Thomas for being the recorder and layout editor (in between being a professional writer).

Without such volunteer help, we wouldn't exist.



East Bay

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NAMI EAST BAY 2019 MEMBERSHIP

Please check your mailing label. If the code "19" is over your name on the right side of the label, your dues are current through 2019. If your mailing label indicates a previous year, or nothing at all, your dues are not current.

We urge you to mail your 2019 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

Name: _____ Phone No.: _____

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