NAMI EAST BAY NEWSLETTER

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

March-April 2019

When the Caregiver Can No Longer Provide Care

Wednesday, March 27

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** will discuss 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.

Dale is an attorney who focuses on special needs trusts and is the trustee of the Golden State Pooled Trust. 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.

Grabowski is Director, Independent Living/Case Management, with EBI and started out with them 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 stepped into a new role providing Case Management/Advocacy support.

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 March 13, April 10, and May 8.
- **Support and Share Group for Families of Children, Adolescents, and Young Adults** is held on the 3rd Tuesday of the month: March 19, April 16, and May 21.

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.

Last Issue Alert

If the number on the upper right side of your mailing label indicates a numerical month/year date, that is your membership expiration date. If there is no such number, you are not on our membership rolls. The upper left-side number notes when we first entered your name into our computer system.

Long story short, our postage costs (printing and mailing) are our biggest expense and we need to cut back and take a harsh look at our mailing list. We'll remove your name if you've been receiving our paper newsletter for some years and haven't been an active or passive participant in the affiliate. We of course prefer that you become a paid member ($40 individual, $60 household, $5 low income) but we're fine about sending you our newsletter by email if we have your email address. Let us know. Or, you can read it on our website. We haven't done mail purging for some years and the time has come.

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SPEAKER NOTES

Outpatient Treatment in Alameda County

Summarized by Thomas T. Thomas

Our January 2019 speakers were **Penny Bernhisel,** award-winning Program Manager of the In-Home Outreach Team (IHOT) and the Assisted Outpatient Treatment (AOT) programs for Alameda County Behavioral Health Care Services, and **Francesca Tenenbaum,** Director of Patients' Rights Advocates for the Mental Health Association of Alameda County. Bernhisel is a social worker having broad experience with those living with serious mental illness and received the Mental Health Achievement Award in 2017 for outstanding contributions to the field. Tenenbaum regularly joins her in training law enforcement and clinicians for the IHOT/AOT programs and issues around involuntary holds under Welfare & Institutions Code 5150, particularly about the definition of "gravely disabled."

IHOT[1] provides intensive outreach and engagement, mental health screening, and in-home engagement for individuals with a history of hospitalizations or law enforcement encounters, and who are not currently engaged in services. AOT, based on a recovery-centered model, is an intensive community support service for the seriously mentally ill who are at great risk for hospitalization. Both are relatively new evidence-based practices offered by Alameda County with funding under the Mental Health Services Act. Both programs are also the result of sustained family advocacy—for AOT, over a two-year period—and are relative newcomers to the county.

In-Home Outreach Team

IHOT is currently practiced only in Alameda and San Diego counties. It links individuals to the vast array of support programs in Alameda County, trying to avoid unnecessary hospitalizations and reduce interactions with the criminal justice system.

The IHOT mobile team includes a clinical leader/manager, licensed eligible case manager, two peer specialists, and a family advocate. The team does not provide treatment but tries to engage people who are otherwise reluctant to seek outpatient mental health services. The county currently has four such teams, each serving up to 25 individuals, for a total program census of about 100 people.

The criteria for outreach are that the individual have a serious mental illness, be reluctant or resistant to accepting outpatient services, and be eligible for or receive Medi-Cal benefits. If the individual is a Transition Age Youth on his or her parent's medical insurance, the team can help with the transition to Medi-Cal. The individual should be at least 18 years of age with no upper age limit, although the county has a Geriatric Assessment and Response Team for individuals 65 and older.

The team does not directly solicit referrals from individuals with mental illness but will take referrals from anyone—family members, store owners, police officers, anyone involved with the individual—and then go wherever the client is located. While IHOT will receive information and referrals from the police, the team will not report back to them for reasons of confidentiality. The IHOT team will stay involved with the individual for three to six months after he or she is engaged with services.

The team does not provide support for families. But if a family member thinks an individual is heading for a 5150 situation, Bernhisel said, they can be proactive and contact IHOT—or the Mental Health Association or the Family Education and Resource Center. There is also a form, AB 1424, which lets the family legally communicate with mental health clinicians about the medical history of a person under an involuntary hold.

Assisted Outpatient Treatment

The IHOT team is the first stop on the way to Assisted Outpatient Treatment (AOT). This program is an outgrowth of Laura's Law, referring to a murder in Nevada County, and is modeled on Kendra's Law in New York State. The intention is to keep both an individual with severe mental illness and the community safe by preventing people from deteriorating to the point that they need to be involuntarily committed. In its implementation in Alameda County, the court has ruled that the county can provide services

[1] This program is distinct from the Homeless Outreach Team (HOT) as practiced in San Diego and in the City of Berkeley for the past year. HOT collaborates with police and seeks self-referrals on the streets and in homeless camps, while IHOT waits to get a referral before approaching an individual.

but cannot order medication.

AOT is a civil court process, not criminal. It is also not a conservatorship; so the individual maintains his or her rights. The judge supervising treatment gets a report every 60 days. The county can provide services for six months and then, if the patient is still treatment resistant, renew for up to two more six-month periods after that. However, the program has not been in existence long enough to test 18 months of resistance to treatment.

To be eligible for AOT, an individual must meet all nine criteria in the Welfare & Institutions Code: (1) Be 18 years of age or older. (2) Suffer from a defined mental illness. (3) Be unlikely to survive safely in the community without supervision. (4) Have a history of lack of compliance with treatment, so that the person's mental illness has factored in either (a) receiving two or more hospitalizations in the past three years, or (b) committing serious and violent acts of harm toward self or others in the past four years. (5) Have been offered a treatment plan and continues to fail to engage in treatment. (6) Is substantially deteriorating. (7) Participation in AOT would be the least restrictive placement necessary. (8) Participation in AOT would prevent a relapse or deterioration likely to result in grave disability or serious harm to self or others. (9) Would benefit from assisted outpatient treatment.

On that last point, about benefitting from treatment, Bernhisel noted that while the mental illness may include dual diagnosis with substance abuse, AOT is not a criminal process and not suitable to someone whose drug use is unlikely to respond to treatment.

Because the AOT law has "no teeth," Bernhisel said, "You need to have a trauma-based approach. All behavior is in the context of trauma." She spoke instead of the "black robe effect," meaning the implied power of a court and a judge to gain the client's respect and eventual adherence. Bernhisel described the current judge in charge of Alameda County's AOT Court as practical, down-to-earth, and caring about the individuals whose cases she oversees.

The AOT program has a current census of 21 individuals and a capacity of 30. In the program's history, only four individuals have left—meaning they disappeared from treatment for six months or more.

W&I Code 5150 and the Definition of "Gravely Disabled"

To be placed under an involuntary hold in California, an individual must be processed according to the Welfare & Institutions Code 5150. This part of the law allows an individual who is a danger to self or others or gravely disabled to be held for 72 hours pending a hearing, then held for 14 days after that, and if judged appropriate after a further hearing, held for another 14 days.

Most "5150s" in Alameda County are issued by the police, but some counties use clinicians, and Francesca Tenenbaum would like a change to that model. She is also working with local police on how to write a good 5150, so that patients arriving at a crowded facility like the John George Psychiatric Pavilion—when their bodies are full of adrenaline and their mental state is at its sharpest—are not "triaged away" when they actually need care.

Under the law, "gravely disabled" is a complex criteria, she said. The technical meaning is that a person is not able to provide for basic personal needs such as food, shelter, and clothing. But in reality, it means that the person cannot *safely* care for him- or herself. For instance, some people have the awareness to take good food from the dumpster at a grocery store, while someone gravely disabled might not distinguish food from non-food material.

"Under the law," she said, "if a person can survive because of family assistance, then they can only become 'gravely disabled' if the family kicks them out of the house. But if the person has deteriorated to the point that you cannot keep them going, then you have to say you can't keep them alive. The key word is 'safely.' "

Even in a family situation, a person with paranoia or delusions might reject the food the family offers. Or a person with diabetes might try to exist on an all-sugar diet, or drink excessive amounts of water and risk death through electrolyte imbalance.

As to advice for families in this situation, Tenenbaum advised them to fill out Form AB 1424 and not give up. "Persistence pays off," she said.

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

Musings

Many, many years ago, way before the Internet and even TV, my sisters and I loved our comic books: buying, storing, and swapping them. So ... even now I have a couple of newspaper comic strips I like to read and if that makes me seem shallow and immature, so be it. One I enjoy is *Zits,* about a teenager and his befuddled parents. Teenagers are much more palatable in a comic strip than in real life sometimes. So in the strip I want to describe, the mom is sending him off to school and then steps back, aghast at what she sees. In the last panel, we see the kid walking in the snow and ice, wearing only shorts, a tee shirt, and sandals, thinking to himself, "I don't suck up to winter."

In case you're wondering where I'm going with this, consider how many of our teenage and young adult relatives "don't suck up" to a diagnosis of mental illness. The mental health professionals don't diagnose this as No-Suck-Up-To-ism; they have a much fancier term, Anosognosia (lack of awareness).

Think back on your adolescence, an insecure worrisome time for many kids, and consider how you would deal with being given that diagnosis. There's a huge psychological issue of denial—and that's totally understandable, given aspects of stigma along with teenagers' common feelings of invincibility. It's probably the main issue brought up by parents: s/he doesn't think there's anything wrong.

Research, however, is telling us that it may be more than a psychological issue. Anosognosia is a common sign in victims of stroke and dementia, both neurological conditions. The posthumous brain of an individual with schizophrenia shows anatomical distortions in the frontal lobes, where abilities around executive function and self-reflection reside. Research is ongoing but still not conclusive. Interestingly, medication generally does act to diminish the anosognosia, and that suggests that there is a neurological basis. Yet the act of taking meds also suggests some acceptance that there is something amiss. There is pushback on this concept of lack of insight from some who feel that this justifies involuntary treatment if a person is not aware of a disorder.

What comes first is our families' feelings of complete frustration with this condition. I scanned the literature for treatment recommendations, but the cupboard was generally bare. Xavier Amador's name is mentioned often in conjunction with his book, *I'm Not Crazy, I Don't Need Help,* and we recommend this. And, as mentioned above, whether we like it or not, meds do work. Also, some group treatment interventions which have an AA-type ritual of introducing oneself along with one's diagnosis are helpful for some people. Motivational Interviewing (MI), Cognitive Behavioral Therapy (CBT), and LEAP (Listen, Empathize, Agree, Partner) are recommended by Dr. Amador.

Lastly, communication is crucial, and discussing issues without using psychiatric terms may be helpful. This presents the opportunity to put a softer narrative on a psychiatric diagnosis by using familiar comfortable descriptors, such as "shaky" or "confused"—whatever calms or pseudo-normalizes a dreadful situation. In some cases, a conversation that doesn't demand face-to-face contact, such as side by side in a car, may be more effective, since facial expressions can be distorted and misinterpreted.

Your loved one may not "suck up" to a psychiatric diagnosis. And, let's face it, none of us wants something that complex and worrisome attached to our relative. Hang in there ... you're not alone.

—Liz Rebensdorf, President, NAMI East Bay

Schizophrenia and Related Disorders Alliance of America (SARDAA)

A board member recently shared information about current advocacy efforts for the hoped-for reclassification of Schizophrenia as a neurological disorder. This introduced us to the nonprofit Schizophrenia and Related Disorders Alliance of America (SARDAA), whose website is sardaa.org. We recommend you take a look at the site along with the comprehensive, well researched letter and join the advocacy by sending on the letter or your own.

The letter provides an excellent overview of the disorder, describing the research evidence as "overwhelmingly ... indicating that the disease is a brain-based highly heritable ... neurodevelopmental disorder. ... Prevailing hypotheses ... include dysregulation of the dopamine, glutamate and GABA neurotransmitter systems. Synaptic pruning—a critical process that refines neural circuits … is perturbed, in

particular during adolescence ... significant enough to show decreased grey matter volume in structural MRI studies of schizophrenia."

This disorder shares features with the two neurologically based disorders of Alzheimer's and Parkinson's disease (brain/cognitive deterioration along with social/sensory/motor/affective disturbances, brain structural and functional changes, clinical rather than lab-based diagnosis, genetic basis, treatment via meds and research approaches). The main difference is the paucity of timely and appropriate care for the individual with schizophrenia, with "striking rates of patients being untreated, homeless and incarcerated ... associated with much suffering, debilitation and public health cost."

So if you'd like to encourage a more humane and studied approach to mental illness that fully realizes that we are dealing with a brain/neurological disorder, we recommend that you take a look at the SARDAA website and do some advocacy towards that end.

Note: SARDAA has recently merged with Parents for Care, a 20,000-member national support and advocacy group which assists families living with mental illness. The organization's name will change under SARDAA to Families for Care.

New Peer Resource in Alameda County

Sally's Place Peer Respite Home is a voluntary, short-term program, staffed by peers, that provides non-clinical crisis support to help people find new understanding and ways to move forward with their recovery.

It operates 24 hours a day in a homelike environment with six beds. The address is 1525 B Street, Hayward. LaFamilia is the agency running the services, and they prefer a call before dropping in (510-963-9849).

Eligible individuals must be age 18 or older, have mental health distress, have an identified place to stay in the county (e.g., not a homeless shelter), independently manage medical needs, and voluntarily agree to engage in services. Maximum stay is 14 days. This is only for Medi-Cal or uninsured consumers.

Urge California to Apply for an IMD Exclusion

An IMD is an Institute for Mental Disease facility that can offer more than 16 acute inpatient hospital beds. The federal IMD exclusion has barred the use of Medicaid payments for these facilities.

Historically, the exclusion was considered a preventive measure against the "warehousing" of individuals with mental illness. In the light of the housing crisis and the recent instances of mass shooting violence, there are efforts being put forth to have waivers given to states to address society's needs for an increase of treatment interventions. Waivers will be awarded where robust community-based treatment services are offered as well.

The absence of appropriate mental health treatments offered within a full range of service options has brought us to the point where jails and prisons have become the primary dumping ground for our family members. So we join with NAMI California and other NAMI affiliates across the state in advocating for application for the waiver.

Please address your concerns regarding this to Jennifer Kent, Director, Department of Health Care Services, PO Box 997413, MS 0000, Sacramento, Ca 95899-7413 or jennifer.kent@dhcs.

PEER Support

We're posting this information again since we get so many requests. There are peer support groups across the county in Hayward, Union City, Pleasanton, and Fremont. These are CONNECTIONS groups and the NAMI-trained facilitators are individuals who are in recovery themselves. Groups meet once or twice a week, depending on the site. For specific information, please call our office at 510-524-1250 or Coordinator Kathryn Lum at 408-422-3831.

There are also Wellness Centers sponsored by Bay Area Community Services (BACS). These are all day drop-in programs located in Hayward, Fremont, Pleasanton, and Oakland. For more information, go to www.bayareacs.org and follow the link to Wellness Center.

Lastly, the website www.peersnet.org has a lot of information about WRAP (Wellness Recovery Action Plan) groups and other activities.

NAMI East Bay

National Alliance on Mental Illness

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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

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