NAMI EAST BAY NEWSLETTER

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

November-December 2015

What is the Hearing Voices Network?

Wednesday, November 18

For several years NAMI East Bay has both watched and taken part in a movement to explore alternative perspectives on mental illness. Fueled by the interest, energy, and commitment of Board Member Ed Herzog, the Hearing Voices Network (HVN), which is so popular in Europe, has finally come to the East Bay. Originating in the Netherlands in the 1980s, this movement forms networks and peer organizations with local groups in the UK, Europe, and now the U.S. and other countries. HVN emphasizes the value of exploring the personal and cultural meaning of voices and related experiences. It does not promote any one interpretation of voices, and it underscores the importance of self-determination.

When HVN founder Ron Coleman was in town in April 2014, we offered a paid workshop, with two more since then. In each case, interest and attendance wildly surpassed our expectations, with hundreds of participants, some from other parts of the state and several from out of state. In the sense of having a tiger by the tail, the core group is now becoming a certified nonprofit organization on its own.

Meanwhile, NAMI East Bay has never offered an unpaid overview of this movement for our members. We've also been on the receiving end of some pushback and perceptions that HVN is anti-meds and anti-psychiatry. We have carefully monitored that issue and don't see it in the local presentation. What we do see are family members whose relatives aren't thriving when given the standard services and desperate families who are open to something different. With that in mind, please join us on November 18 (third Wednesday because of Thanksgiving) to hear more.

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 are November 11, December 9, January 13.
- **Support and Share Group for Families of Children, Adolescents, and Young Adults** is held on the 3rd Tuesday of the month: November 17, December 15, January 19.

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.

Winter Family to Family Class

Our annual 12-week, 30-hour Family to Family class will be held Thursday evenings in Albany, January 21 through April 7, 2016. The class offers a comprehensive look at all aspects of mental illness: diagnoses, theories about causes, communication strategies, problem solving, empathy, resources, group sharing, physiology, medications, treatment options, and more.

Teachers will be Tommie Mayfield, Lindsay Schachinger, and Liz Rebensdorf. The class is free but limited regarding number of participants, so contact the office by phone or email to indicate your interest, and one of us will contact you.

Precision Mental Health

At a recent Stanford Mood Education Day, Dr. Lea Williams discussed Precision Mental Health, where treatment is more individually oriented. See the National Institute of Mental Health under RdoC, the Research Domain Criteria Initiative.

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SPEAKER NOTES

In Dealing with Agitation, Use De-Escalation Rather Than Coercion

Summarized by Thomas T. Thomas

Our September presenter was **Scott Zeller, MD,** Chief of Psychiatric Emergency Services at John George Psychiatric Hospital and past President of the American Association of Emergency Psychiatry. Described by one NAMI official as the "Johnny Appleseed of Crisis Stabilization," Dr. Zeller has practiced emergency psychiatry for 28 years, authored numerous articles, written and co-edited several books, and received distinguished honors for his work with crisis treatment of agitation in individuals with mental illness. He has become an expert on reducing the use of restraints, seclusion, and forced injection in the emergency hospital setting.[1]

We also had **Beverly Bergman,** Family Caregiver Advocacy Specialist at John George, and **Francesca Tenenbaum,** Patients' Rights Director for Alameda and San Mateo counties, join the discussion to share their comments and impressions.

"It's frustrating working with medical professionals," Dr. Zeller said, "and getting them to understand that people in the emergency room are not their enemy. That the easiest but most coercive treatment is probably not the best." Many doctors, he said, are most concerned about the safety of their staff. So their solution to an agitated patient is to tackle him with security guards, restrain him, and inject him with strong medications—and if he sleeps for a couple of days, at least the staff is safe. But two-thirds of staff injuries are usually sustained while restraining the patient instead of trying less coercive methods.

Patients experiencing agitation are often in anguish and distress, with racing thoughts, paranoia, and the fear they are in jeopardy. They are often engaged in basic "fight or flight" decisions. Dr. Zeller tells colleagues that such agitation is the equivalent of experiencing "the worst headache in the world." Imagine you had that headache, and people were telling you to sit down, be quiet, and wait for treatment. "Understanding and treating agitation with compassion can be the basis for an overall approach to involuntary crisis care," he said.

In 2010, the American Association for Emergency Psychiatry started work on Project BETA, which stands for ***B***est practices for ***E***valuation and ***T***reatment of ***A***gitation in an emergency setting. More than 40 emergency psychiatrists, emergency room physicians and nurses, mental health clinicians, and patient advocates participated in the project. In 2012, the findings of Project BETA were published in six articles in the *Western Journal of Emergency Medicine* and have since become that journal's most downloaded and frequently cited.[2] These practices apply not just to mental illness, because agitation can occur in people getting out of surgery or suffering a stroke or head injury.

So, what is agitation? Dr. Zeller defined it as "excessive verbal and/or motor behavior"—people talking a bit too loudly or moving around too much. Agitation is a spectrum, he said, from a patient who is irritable and frustrated to the Incredible Hulk smashing cars—but that's the rare end point. But many emergency room staff just think about the agitated patient becoming the Hulk and react in kind.

To deal with agitation, Dr. Zeller formulated the "Six Goals of Emergency Psychiatric Care."

1. Exclude medical etiology of symptoms. Observe the patient and his or her vital signs. Agitation may result from head injury of brain bleeding, a thyroid problem, infection and fever, high or low blood sugar, or some kind of intense pain. Look for signs such as sweating, different sized pupils in the eyes—caused by brain trauma—or low blood oxygen.

2. Rapidly stabilize the acute crisis. Don't waste time, and don't put the patient off until you have time to see him. De-escalate the patient in verbal and nonverbal ways (see below).

3. Avoid coercion. Commands and force only make the patient more scared, hostile, and agitated.

4. Treat in the least restrictive setting. Don't use restraints or a locked room. Make the patient feel relaxed. Avoiding bright lights and confusion is best. John George has created unlocked "comfort rooms," where patients can sit and talk with a clinician.

[1] For YouTube videos of Dr. Zeller's techniques, click on: www.youtube.com/playlist?list=PLkEyLB5TkXVI2gWLVxBYnm3N2MR0niu-2.

[2] To read the six journal articles, click on: http://escholarship.org/uc/uciem_westjem?volume=13;issue=1 or Google "Agitation BETA."

5. Form a therapeutic alliance. The goal is not a doctor-patient confrontation but "we're going to do this together." Often the patient *can't* regain control by him- or herself, so the clinician needs to provide ways—sometimes by offering options and choices—for the patient to take control of the situation.

6. Formulate an appropriate disposition and after-care plan. The goal is for the patient not to end up in this situation again. This goal is actually to put the emergency psychiatrist out of a job.

By following the Project BETA practices and the Six Goals, Parkland Hospital in Dallas, TX, dropped its use of seclusion and restraints by 96% and its use of forcible injection by 94%. Queen's Medical Center in Honolulu, HI, decreased from 20 restraints per month to zero.

John George, which takes patients from all 11 emergency rooms in Alameda County, has developed what Dr. Zeller called the "Alameda Model." Elsewhere, when police are called on a 5150,[3] they may move aggressively and often put the person in handcuffs to take him or her to the emergency room. In Alameda County, because the federal government defines a psychiatric emergency the same as a medical emergency, police will do the initial intervention but then call for an ambulance and paramedics to take the patient. (Crisis Intervention Training [CIT] is being provided to Alameda County law enforcement staff.) About a third of such patients go to the emergency room and then, when medically stable, are taken to John George. They are usually admitted immediately and seen by a clinician in less than two hours. In Sacramento County, the patient may wait an average of 26 hours; in Georgia, it's 34 hours.

The Psychiatric Emergency Service at John George tries to provide one staff member for each six patients, and depending on the time of day, may achieve one for three. They are moving toward zero restraints and have reached 68 days without putting a patient in restraint; they now average two restraints per 1,000 patients. Interestingly, Dr. Zeller said, when the number of restraints went down, the number of forcible injections did not go up. Their treatment emphasizes collaboration and offering the patient what medications have worked for him or her in the past. He noted that oral medications such as the anxiolytic Ativan (Lorazepam) work just about as fast as a forced injection.

"People get hurt when you try to force them," he said. So fewer restraints equal fewer assaults and staff injuries.

Scott Zeller demonstrated for the audience what he calls verbal and nonverbal de-escalation. "It's a bit counter-intuitive, but when someone is agitated, you don't want to be agitated back. You want to be the calm one." Some of his techniques include:

- Stay open, with knees bent and arms at sides. Don't get defensive or ready to fight. Much of the de-escalation technique is based on the patient's perception of your intentions.
- Speak in a calm, soft voice, getting softer each time. Use simple, short phrases and ask positive questions: What do you need? How can I help you? Are you hungry or cold? John George provides a comfort station where patients can get a blanket or something to eat or drink.
- Offer the patient a means of escape. He will be in fight or flight mode, so don't back him into a corner. Make sure he can see a way out.
- Never challenge the patient on what he says. They believe what they're thinking; but you can agree to disagree.
- Give the patient choices and alternatives, which give him or her a sense of control in the situation.

Dr. Zeller pointed out that these techniques work best in a clinical setting but may not always work at home in a family setting, where there may be more of a history. He also noted that these techniques are for short-term de-escalation of an agitated patient; they are not intended as a long-term solution. (In discussion afterwards, some audience members feared that de-escalating the patient might mean they no longer met the criteria of "danger to self or others" and so might not get treatment.)

The Alameda Model is now being tested and applied in seven other places in California, in Portland, OR, and in New Jersey, North Carolina, Connecticut, Arizona, and Illinois.

[3] This is the section of the California Welfare & Institutions Code which authorizes a qualified officer or clinician to involuntarily confine a person suspected of a mental disorder that makes him or her a danger to self or others or gravely disabled.

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 from the President

I have never started this column with a joke, but I want to share this from Malcolm Gladwell in the May 4, 2015, issue of *The New Yorker*:

There is an old joke about an engineer, a priest, and a doctor enjoying a round of golf. Ahead of them is a group playing so slowly and inexpertly that in frustration the three ask the greenskeeper for an explanation. "That's a group of blind firefighters," they are told. "They lost their sight saving our clubhouse last year, so we let them play for free."

The priest says, "I will say a prayer for them tonight."

The doctor says, "Let me ask my ophthalmologist colleagues if anything can be done for them."

And the engineer says, "Why can't they play at night?"

Now, granted I view the world with a set of blinders, but I immediately thought of our NAMI families and the three ways of dealing with issues, as exemplified here by the priest, doctor, and engineer—not to laugh but with the warmth that periodically overwhelms me when I think about the caring and love I hear about from family caretakers as they share about their loved ones' challenges. You are some of the kindest people I have met. I think it goes with the territory of parenting children with disabilities. I just saw and shared a tear-producing video on Facebook where a father dances with his young daughter, who is in a wheelchair and tremendously impacted with cerebral palsy.

Families need to have hope and faith, as does the priest in the story. An individual with a serious mental illness may not lead the kind of life that was anticipated, but families need to have hope that things will get better.

Like the doctor in the joke, we have to be exploring new interventions, whether they be based on the Western model of a neurobiological basis for the illness or other, alternative models with more of an environmental determinant. There sure doesn't seem to be any consistent right answer for every person.

And, like the engineer in the story, we live in a concrete world where problems need to be addressed on a practical basis. Daily living calls for numerous practical informed decisions.

I can only stretch that joke so far though, since there's at least one other major aspect to being a family member that the joke doesn't address—the aspect of advocacy. Our system is broken, and ill individuals are not getting the kind of help they need, either with medical insurance or through the county service delivery system. Families need to advocate for their loved ones and that can take several forms.

A very active family group has been bird-dogging the Alameda County Board of Supervisors regarding a pilot program for AB 1421/Assissted Outpatient Treatment/Laura's Law. Families are advocating to congress regarding HR 2646, the Helping Families in Mental Health Crisis Act of 2015. Others are writing letters to newspapers, calling into news shows, and taking every opportunity to get ideas of change into the public consciousness.

Towards that end, our NAMI East Bay website (www.namieastbay.org) will soon be modified with the addition of another page titled Public Policy. There you will find summaries and links to current legislation, addresses of local legislators, information about advocacy events, and networking opportunities. The page is still being put together but we hope it can provide the information and timeliness that advocacy efforts demand.

—Liz Rebensdorf, President, NAMI East Bay

Learning at the Lakehurst Hotel Project

By Margot Dashiell, Project Co-Director

The Lakehurst Project was under way for several months when Lee (a pseudonym) said he'd be absent. To our dedicated volunteer, who heard him say he was waiting for his case manager so he could wash clothes, that sounded like a lame excuse. The comment would likely have also led many family members, with loved ones living with mental illness, to see Lee as overly dependent. He was able-bodied and full of energy; why couldn't he wash his own clothes? Following the residents at the Lakehurst Hotel, who participated in a program of activities and congregate lunch three mornings a week, the Lakehurst Project staff came to understand what the average citizen, even the average family member, does not understand about realities of life on SSI. People who exist on that income alone, without subsidized

housing or the benefit of a room in a family home, are living in poverty.

Lee was well groomed; his clothes were always clean and pressed. Pride would not allow him to show up for the yoga or music groups in soiled clothes. But washing them required detergent and money for the washing machine. Fortunately, he had a responsive case manager who would eventually arrive with the wherewithal he needed to complete his laundry day. But many residents, all of whom live with serious mental illness and/or substance disorder, didn't have the benefit of intensive case management. People who work with those living on Supplemental Security Income (SSI) are sensitized once they do the arithmetic. Rent at the hotel averages $815/month. If a person is surviving on an SSI check of, say, $1,000/month, food may well take priority over soap. And still he or she would not have enough cash to cover meals for a month.

On Monday through Friday, the Lakehurst serves what management refers to as a quite modest breakfast and dinner. For lunch, and for weekend and holiday meals, the kitchen is closed and residents are on their own. How does a person manage to cover necessities like lunch, weekend meals, toiletries, clothes, and transportation—even with a disability subsidy—on $185/month? They don't. Sure, residents learn what soup kitchens are open on which days, but if they're not within walking distance, they are unlikely to get in line. Many admitted that they face repetitive periods of hunger.

For the many years now that I have facilitated support groups for family members, I have never heard one say, "My son or daughter is hungry." Family members are knocking themselves out to see that enough food, clothing, and amenities beyond the basics are available to loved ones facing mental illness. But what about those who don't have family members to fill in the large gap in resources once the SSI check covers the basics? Those are the people we see panhandling on street corners or, if not lucky enough to get housing, we see them rolled up in a blanket in a downtown doorway. For those living with serious mental illness, they are the people who are at highest risk of the foreshortened life span we hear so much about.

It will take time, but perhaps what Helena Hansen, MD, PhD (Department of Psychiatry, New York University), advocates will come to pass—medical education that trains providers in "Structural Competence." It is widely known, she says, that the social determinants of health are things like poverty, housing, employment, stress, and fresh food, and that until providers lend their considerable credibility in advocating for institutions and communities to provide adequately for necessities, the U.S. will continue to have poor outcomes in physical and mental health. Look for the blog she writes with Dr. Jonathan Metzl at http://www.structuralcompetency.org. Its subtitle is "New Medicine for the Institutional Inequalities that Make Us Sick." Changes in policies and practices would help many more than Lee.

(Note: Our Vice President Margot Dashiell has been on the front lines with her 18-month Innovations project dealing with Isolated Adults with Serious Mental Illness who have been living in an Oakland single-room occupancy residence. Funded through the Mental Health Services Act/Prop 63, the project is being wrapped up now and findings from it and others are being consolidated, with reports back to the community anticipated this winter.)

Family Game Night

Our first attempt last month to offer a social evening for families and relatives seems to have been generally successful, with participants playing board games, enjoying pizza and prizes, and engaging in some interesting discussions. So we're going to do it again on Thursday, December 3, 5-7 pm. The only ground rule is that you must let us know you're coming, so we can plan for ample space and pizza. Leave us a message by phone or email.

Paid Research Study Opportunities

- Youth with bipolar disorder—sleep study, dailyrest@stanford.edu, 650-736-2689, at Stanford University.
- People with bipolar disorder, minor symptoms, under care—biofeedback breathing training, calmprogram@gmail.com, 510-542-8969, at UC Berkeley.
- People with bipolar disorder—10 weekly group sessions, interviews/questionnaires, 510-542-8241, at UC Berkeley.

NAMI East Bay
National Alliance on Mental Illness

980 Stannage Avenue
Albany, California, 94706
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Please check your mailing label. If the code "15" is over your name on the right side of the label, your dues are current through 2015. If your mailing label indicates a previous year, or nothing at all, your dues are not current.

We urge you to mail your 2015 dues now. And if you can afford to add a bit more, please do so. Your $35 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, $35 per year** ☐ **Open Door Membership, $3 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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