
NAMI EAST BAY NEWSLETTER

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

November-December 2016

Current Research on Emotion and Mental Health

Wednesday, November 16

Ann Kring, PhD, is a member of the Institute for Personality and Social Research at the University of California, Berkeley. She received a BS in psychology from Ball State University and her MA and PhD in clinical psychology from the State University of New York at Stony Brook. Her current research focus is on emotion and mental health, with a specific interest in the emotional features of schizophrenia, including the negative symptoms, decision making, and the linkage between social life, cognition, and emotion. In addition, she studies the ways in which people differ from one another in emotion and expressive behavior and the linkages between social context and emotion.

Dr. Kring has received numerous awards, including a Young Investigator award from the National Alliance for Research on Schizophrenia and Depression, the Joseph Zubin Memorial Fund Award, and a Distinguished Teaching Award from UC Berkeley. She is past president of the Society for Research in Psychopathology and president-elect of the Society for Affective Science. She is the author eight books and several scholarly papers, as well as having served on the editorial boards of top journals in the field.

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 9, December 14, and January 11.

- **Support and Share Group for Families of Children, Adolescents, and Young Adults** is held on the 3rd Tuesday of the month: November 15, December 20, and January 17.

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.

Help Represent the Family Voice

The family voice continually needs to be represented on Alameda County Behavioral Health Care committees. If you can give an average of a couple of hours a month to committee work where you represent the family perspective, let us know. Some participation opportunities, such as the Mental Health Advisory Board and the Mental Health Services Act Stakeholder Committee, are a bit more involved in terms of recommendation and vetting. Others, such as the Training Committee and ISP (Vocational Rehabilitation) are currently staffed but are shareable. The county-funded speakers bureau will also be incorporating the family voice for community presentations. Some of us have been carrying this responsibility for family voice input for some years and are ready to share it. If interested, let us know and we'll sit down and bring you up to speed. For our Contra Costa County families, we'll connect you with the appropriate personnel.

Rockridge Chorale

We are always advising families to take care of themselves and find things to enjoy in life and distract from the stress. In August, The Rockridge Chorale (www.rockridgechorale.org) graciously supported

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SPEAKER NOTES

Long-Term Care Planning

Summarized by Thomas T. Thomas

We families share an overwhelming concern about the future: for when we are gone and our ill family members are on their own. At the September 28 meeting, we gave this conversation a jump start by having two experienced professionals address our group. **Linda Durston, PhD, JD**, is a local attorney whose practice involves special needs trusts, incapacity planning, and elder law, among other topics. **Sharon Toth, LCSW, CLPF** is Executive Director of IMT Associates, a professional fiduciary agency, which offers trustee, conservatorship, and case management services with a multidisciplinary staff.

Long-term planning, Durston explained, is for if and when you become severely disabled and need skilled nursing and custodial care for your basic needs. The only agency that pays for long-term care is MediCal, while Medicare will pay only for care immediately after you get out of the hospital but not for custodial care. So everyone should plan for long-term care. “The key question is,” she said, “if you needed regular custodial care, would you prefer to spend down your estate to two to three thousand dollars before accepting state assistance? Or would you want to protect your assets for your spouse and your kids?”

Although your actual plan will depend on your situation, Durston recommended the California Advocates for Nursing Home Reform (www.canhr.org) as an excellent resource for the financial considerations of qualifying for MediCal long-term care and for evaluating long-term care facilities.

In planning for care for a parent or child, either married or single, she said, you need to know what assets will be available, who owns them, whether they are sufficient for your planning goals, and how they would be accounted. For example, cash is counted but a house or first car is not, and a retirement account is not—provided you are taking minimal distributions. So, if you had both an investment account and a home mortgage, the plan might be to use the money in the account to pay off the house. You also have to plan for MediCal’s attempts to recover your assets after you die, and this might include transferring property to your spouse or kids.

The four basic parts of an estate plan, Durston said, are a revocable living trust; a pour-over will, to put assets into the trust after you die; a durable power of attorney, for financial management; and an advance health-care directive. The trustee should have the power to move property between the husband and the wife, make gifts to children and others, and create and amend special needs trusts as necessary.

A special needs trust (SNT) is a trust arrangement that holds and provides for the management and distribution of property for the benefit of a person with special needs. The trust is an agreement between the grantor and the trustee, including successor trustees. The trust contains any kind of assets that you are willing to put into it and the trustee is willing to manage. Typically, the beneficiary is someone who has special needs, is usually but not always disabled, and qualifies for means-tested public benefits like Supplemental Security Income (SSI) and Medi-Cal.¹ The trust is designed to have little or no effect on the beneficiary’s eligibility for these benefits.

Generally, in 2016, SSI pays \$889 a month to adults living on their own.² This benefit is supposed to cover food and shelter, which includes electricity, gas, property taxes, and other home expenses. So any money distributed from the trust to pay for these expenses will reduce the benefit. The trust can only distribute up to \$20 a month in cash without reducing benefits. But the trust can provide for any other living expenses such as transportation, entertainment, and education. However, the SNT must prohibit the beneficiary from directing distributions from the trust or revoking it.

Such a trust when created as part of your estate plan is called a “third-party special needs trust.” Because situations can change, it can be made revocable by the grantor. The third-party trust lets the special needs person benefit from inherited or gifted

¹ The Social Security Administration operates both Social Security Disability Insurance (SSDI, including Medicare) and SSI. Medicare and SSDI are earnings-based and have no limits on allowed resources or unearned income, although they do limit earned income. SSI and MediCal are needs based, have limits on owned resources (\$2,000 for a single person, \$3,000 for married), and limit both unearned and earned income.

² The amount differs if the adult is living in a board and care, is homeless, or is blind. If the person lives in someone else’s home, or someone else contributes substantially to rent, the benefit is reduced by \$260 a month.

funds and still retain eligibility for public benefits. When the beneficiary dies, the assets can then pass on to other beneficiaries the grantor has designated with no payback to the state. The trust can also be drafted to allow distributions to, or for the benefit of, others besides the beneficiary, such as the grantor's or the beneficiary's children.

Sharon Toth is a licensed fiduciary with IMT Associates in San Leandro (www.imtassociates.com), the longest running, full-service private professional fiduciary agency in Northern California. She started as a licensed social worker, but fiduciaries can come from all backgrounds, including real estate, accounting, and financial management. The process of becoming a fiduciary includes education, testing, licensing, and continuing education. IMT Associates specializes in working with the mentally ill and will do a home visit before taking on a client.

In writing an estate plan, Toth said, it's important to choose the right trustee. An adult child or sibling who is currently well might get sick and die before becoming the trustee. It's also important to find someone who will respect what's important to you. Toth recommends finding a neutral third party—one resource is the Professional Fiduciary Association of California (www.pfac-pro.org), representing more than 600 fiduciaries—and interviewing two or three people to find “the person who feels right to be taking over your life.” Also, your estate planning should designate someone who has the power to remove and appoint the trustee, fiduciary, or financial manager.

The fiduciary not only manages the beneficiary's money as trustee but also helps with his or her living situation as a case manager. This may include services like taking the client to medical appointments and arranging for his or her long-term care. If the fiduciary will be working with a disabled adult or child, she said, it's important to have him or her meet the beneficiary before the trust goes into effect. “The fiduciary will be replacing Mom or Dad in the beneficiary's life. You don't want this person to be a total stranger at what's already a stressful time.”

The fiduciary becomes the advocate for a beneficiary with mental illness, dual diagnosis, or a developmental disability. They work to get the client every bit of service he or she deserves—which in this political and economic environment usually requires someone who must be willing to “chew nails”

through the application and approval process—and through the inevitable refusal and appeals.

In working with difficult clients, who can be unreasonable and demanding, especially where money is involved, Toth said, “Our job is to love the unlovable.”

The fiduciary is like a safety net, not micromanaging the client's life but making sure he or she gets what is needed. “A good fiduciary knows when a person is well enough to have some independence. That gives the person dignity and self-esteem.” IMT Associate's services vary, depending on what the client is capable of doing, and the fiduciary renders a full accounting, including fees, at least once a year.

Q. What do these services cost?

A. IMT Associates charges \$150 an hour, and bills in tenths of an hour, like an attorney. Non-professional services, such as home health aides, charge \$35 an hour. The firm also considers the size of the estate and won't take on a client whose assets are less than \$750,000. “For a young person on a special needs trust,” Toth said, “that amount has to last them for a lifetime.” For those with less assets on hand, there are ways to pool with other trusts (see www.proxyparentfoundation.org).

Q. What happens if the money runs out?

A. The fiduciary's job is to manage the money so that it doesn't run out. Sometimes this can mean reducing services to the beneficiary.

Q. Can a special needs trust be activated while the grantor is still living?

A. Sometimes. If the parents are divorced, for example, they may want to start the trust to take care of a disabled child. Or they may want to start the trust to see how it works while they are still alive and able to make changes. A trust can also be set up if the beneficiary has assets, such as an accident settlement, that will need protecting.

The final recommendation of both Durston and Toth is to find a good lawyer and set up an estate plan and advance directive—and do this sooner rather than later. “You may not think you need it at age 30 or 40, but life is full of surprises and your situation can change quickly.”

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 from the President

Several years ago, I had the good fortune to take a trip to Italy. Among all the history, art, and wonderful experiences, one thing stood out and it continues to give me goosebumps when I talk or think about it. One of the focal points of the Sistine Chapel is Michelangelo's fresco The Creation of Adam. This is an image, widely available, of the Creator reaching out to just about touch the fingertips of Adam, who is lollygagging on a hillside. Google the image and take a good look at it. The structure which supports God, surrounded by cherubs, is the human brain. So God is giving life to Adam, but he's also imparting cognition, memory, and emotion across the synapse of their fingers.

The genius of Michelangelo was not informed by CAT scans or MRIs. He studied anatomy and looked posthumously at brains, and he seemed to be acknowledging that there was more than meets the eye. One scholar advances the theory that a particularly sad cherub is placed strategically at an area of the brain associated with depression. Who knows?

I keep searching for something truly meaningful to make of all this. The only thing that comes to mind is that the human brain, along with outer space and the deep ocean, remains one of the last frontiers to conquer. I feel sometimes that we're still in our covered wagons or trusty galleons, traipsing across the plains or watery terrain, trying to find new lands and, basically, answers. I watch my grown son stand for five minutes in front of a toy display at Target, apparently riveted by what he's seeing. What is going through his brain? What neurological connections are firing? The newfangled equipment, such as a functional MRI, can tell us that, in the brain of a person with schizophrenia, there may not be a focal point for the disease and that the processing is more diffuse and unfocused—but does that explain the over-focused and ritualized behaviors that are comorbid with the disorder? So many questions, so few answers.

There's a lot of relevant work going on currently, following differing research paths of inquiry. The consensus appears to be that the brains we've evolved with are susceptible to many environmental stressors, along with genetic and physiological vulnerabilities that affect the biochemistry and neuro-

logical bases. When the factors that inform the nature-nurture dilemma play out—perhaps haphazardly and with certain extrapolations—you may get a brain affected with the dreadful disorder of schizophrenia, or perhaps the genius of Michelangelo, or sometimes both. Someday we will have an answer ...

—Liz Rebensdorf, President, NAMI East Bay

Rockridge Chorale (From Page 1)

NAMI East Bay with a delightful concert on a magical afternoon. The group is now looking for singers to share the fun. You should love music of all genres, be willing to work hard, and be able to sing on pitch. Contact Devi Jameson, the director, at devi_jameson@rockridgechorale.org.

Focused Support Groups (Other Than NAMI)

Hearing Voices Network: Based on the Hearing Voices movement, this is a monthly group for family members specifically to learn and explore compassionate alternatives and approaches to being with, understanding, and supporting our loved ones who experience voices, special messages, and extreme states. Meets the third Thursday of the month, 6:30-8 pm, at the NAMI office. All are welcome.

Connections: This group for consumers is held on the second and fourth Saturdays, 11-12:30, at TeleCare Heritage, 2633 E. 27th Street, Oakland. (Also in Union City, second and fourth Tuesdays, 6:30-8:00 pm). The groups are recovery support groups led by trained consumer facilitators. For information, contact Bev at 510-835-0188.

Spouses and Partners: In our support groups, most participants are parents of relatives with mental illness, and there are common issues that are not necessarily relevant to our members who are husbands or wives or partners of individuals with psychiatric issues. Meetings of the partner group are held on the first Mondays of every month except when there is a holiday. Meeting site is a local restaurant. The remaining 2016 dates are November 14 and December 5. For more information and/or to

RSVP, contact Karen at kmuhlin@gmail.com or Sandy at sandymalloy@earthlink.net.

Focused Advocacy Group (Other Than NAMI)

Voices of Mothers and Others (VOMO): This is a grassroots movement of Alameda County families who have loved ones who suffer with severe mental illness and who are advocating for change to our mental health system. They meet once monthly and their mission is to work towards the removal of barriers to treatment and the redirecting of resources and programs to benefit those suffering with serious mental illness. They are advocating for better availability of and access to appropriate medical treatment, supportive housing and community resources. If you are tired of being told, “There’s nothing more you can do” or “You have to let them hit rock bottom” and would like to be part of this movement, contact voicesofmothersandothers@gmail.com.

Peer to Peer Education Class

The NAMI Peer to Peer Education Class is a free, ten-session course for adults living with mental illness. Within the educational setting, the focus is on recovery with respect, understanding, encouragement, and hope. Starting February 13, the class will be held weekly for two hours and is taught by trained peer mentors. Contact Mary Dell at 510-329-8499 or mdell567@gmail.com for information. This class is sponsored by our sister affiliate NAMI Alameda County (510-334-7721).

Housing Updates

Vote for the Alameda County Affordable Housing Bond (A1). This \$580 million bond will pay for local affordable housing. Mental health advocates had early and consistent input into this measure, insuring that those who are homeless or vulnerable to being homeless or living on SSI may have some viable housing options. Other low-income groups are also being targeted for housing relief. Information is at www.acgov.org/board/housingbond.htm.

Supportive Housing Collaborative is pursuing a partnership with the Housing Consortium of the East Bay (HCEB). The latter has a history of housing development for specialized groups. Interested family members are invited to join our group, which has gone through growing pains this last year but has achieved some unity and shared goals.

Community Living Facilities Networking, a steering committee of providers and family members, is interested in upgrading the unlicensed room and boards through quality standards, support through training and problem resolution, and resource development.

Family to Family Class

Here’s a reminder that our annual winter Albany Family to Family Class is taking registrations now. The 12-week class covers all aspects of mental illness in a supportive framework of content and interactive sharing. We will be running from mid-January to April, Thursday evenings 7-9:30 pm. No drop-ins. Contact the office at 510-524-1250 or email us at namieastbay@earthlink.net to start the simple registration process.

DVDs Available for Loaning Out (Thanks to a Grant from West, Davis, and Bergard Foundation)

- *How the Brain Forms New Habits: Why Willpower is Not Enough*, George Koob, PhD, Professor of Neuroscience, UCSD - 4 DVD set.
- *Reasoning with Unreasonable People: Disorders of Emotional Regulation*, Joseph Shannon, PhD, Clinical Psychologist - 4 DVD set.
- *Listening to the Body: Understanding Stress-Related Symptoms*, Bill Sieber, PhD, Clinical Professor of Psychiatry, UCSD - 4 DVD set.
- NAMI California Convention Keynote Speeches - 1 DVD each:
 - *Curing Schizophrenia One Biotype at a Time*, Cyndi Weickert.
 - *Mental Health Recovery with Gangs in Los Angeles*, Fr. Greg Boyle.



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NAMI EAST BAY 2016 MEMBERSHIP

Please check your mailing label. If the code "16" is over your name on the right side of the label, your dues are current through 2016. If your mailing label indicates a previous year, or nothing at all, your dues are not current.

We urge you to mail your 2016 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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