

The Dental Voice for Mental Health

By Lisa Knapp Stillman



Lisa Knapp Stillman

It has been two years since my son, Jordan, decided to leave his life of suffering due to a diagnosis of a severe mental illness. Jordan was my sunshine. He is

also my inspiration to do something to help in the world of mental health.

I am a dental hygienist and I watched Jordan's teeth deteriorate from dry mouth due to the side effects of his medications. This made me realize that mental health care recipients are being "left out in the cold" when it comes to oral and dental health. I wrote an article in the October 2008 NAMI Voice titled "Medication, Devastation, Tooth Preservation" that discussed the overwhelming need of dental care for those experiencing mental health issues. Due to medication-induced xerostomia (dry mouth), poor oral hygiene and lack of access to care, the dental needs of people living with mental illness remain severely underserved.

After visiting many mental health facilities and speaking to mental health care professionals,

I am shocked to learn that xerostomia is not usually seen as something that decreases quality of life: it most certainly does. More than 700 medications cause xerostomia. A person with normal saliva flow has no idea how miserable xerostomia can be. Without saliva and its emollients, a person cannot move their food around, chew or taste their food. Saliva is essential for fighting infection and maintaining the integrity of a healthy tooth.

Dental Voice for Mental Health is a project created by my sister and I to increase awareness of oral health needs for people receiving mental health treatment. This project has consisted of going to the 2008, 2009 and 2010 NAMI National Conventions to set up oral health booths that offer dental health education, product knowledge and numerous samples for the attendees. The first year my sister and I ran the oral health booth, I funded the project myself. From the meeting attendees, we learned how necessary it was to be there and teach mental health care recipients, professionals and caregivers oral health education. In 2009, NAMI created a Wellness Center for the National Convention and invited our oral health booth to be included. That invitation helped us to reduce our

costs and, with more dental companies donating samples, our booth was quite a hit! I was honored with a letter of appreciation from the NAMI Executive Director Mike Fitzpatrick.

I would like to take this booth "on the road" and offer this much-needed information to the mental health care professionals directly by attending their prospective professional venues. By reaching out and educating the psychiatrists that prescribe medications, psychiatric nurses and social workers, this oral health care information will in turn be given directly to their clients. For example, instead of mental health care professionals suggesting "water" for a client complaining of dry mouth, they

(cont. page 8)

ALSO IN THIS ISSUE

A Word from the ED	2
Steve Feinstein	3
NAMI HelpLine	3
Guardianship?	4
NAMI 2010 Convention	5
Army Troops Run 5K.....	5
Leadership Alliance Corner	6

A Word from the Executive Director



Like many of you, my family has experienced mental illness through many generations. It has had a significant impact on my life as well as the lives of my

siblings and extended family. I truly understand the challenges that arise as we navigate the mental health systems in our communities.

Finding the most effective supports and services are essential to recovery. Understanding what mental illness is, finding out what treatments work and

how to pay for them, locating housing that is safe, affordable and permanent and getting useful information, education and support continue to be essential for my family as it has been for your family.

Over the past 30 years I have worked in government, led nonprofits providing community-based services and served as a state legislator. In the end, I always have come back to NAMI.

My involvement at all levels of NAMI has much to do with my belief that NAMI has the power, ability, skills and people to move forward and get things done. NAMI reaches out to people at the time of their greatest need and provides support and education that they can use.

We are a strong movement. We are grounded in the values of hard work and by a spirit of determination. We battle injustice and discrimination. We are the voice of hope for many.

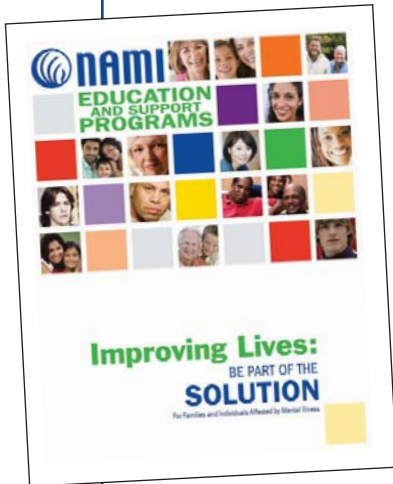
My involvement with NAMI is personal.

Thank you for your ongoing support of NAMI. In these times America needs NAMI more than ever.

Thank you for all that you do.

Michael J. Fitzpatrick

New Education & Support Program Brochure



Spring and summer are perfect seasons for promoting Family-to-Family and the other NAMI signature programs at numerous community and professional events across the country. We are delighted to share the exciting news that over 30,000 copies of the new Education and Support Program brochure *Improving Lives: Be Part of the Solution* has been distributed since January to NAMI State Organizations and Affiliates and to Veterans Health Administration (VHA) facilities participating in the Family-to-Family/VHA Memorandum

of Understanding project. This brochure describes the programs offered by NAMI's Education, Training and Peer Support Center. Some of the satisfied participants of these programs are quoted in this brochure. Wonderful feedback is coming in about using this eye-catching brochure and we're hearing it doesn't stay on resource tables very long! We want to get this brochure into more hands so that people living with mental illness and their families know about our programs and can participate in fall classes and support groups. Let us hear from you if you can use some brochures to help get the word out about the NAMI education and support programs.

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What Do Trained Seals, IRS Paperwork and Futurists Have In Common?

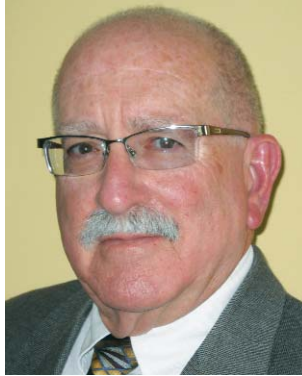
NAMI Board President Steve Feinstein!

Stephen H. Feinstein, Ph.D. was first elected to the NAMI Board of Directors in 2004. Before coming to the Board, he served as president of NAMI Kansas and chair of the State Presidents Council. What sets Steve apart is not his dedication to NAMI, which is considerable, but his vision for what NAMI can and should be.

Perhaps it was an outgrowth of his early work training seals and sea lions that cemented his willingness to work hard to build habits that others might think impossible.

Maybe it was a true understanding of the obligations of running a nonprofit organization—that determination to ensure that NAMI, NAMI State Organizations and NAMI Affiliates all grasp and adhere to the laws of the land and best practices in operation.

Or maybe it was his fascination with looking forward. Whatever the cause, Steve saw something coming that he knew NAMI needed to address and



Steve Feinstein

he's been its tireless champion ever since. Steve's vision was of a NAMI so well-known, so well-organized that we would be known in every community, ready to embrace those who need us the moment they discover that need. He knew that vision—that visibility—was only possible if NAMI adopted mutually agreed upon standards for operation all across the country.

As we prepare to wish Steve well at the close of this second term on the Board, NAMI is also on the brink of embracing new Standards of

Excellence. The Standards embody the vision Steve has championed since his work in Kansas. They speak to our commitment to being a fully inclusive organization, to our mutual accountability, to transparency in our operations and funding. For more information about NAMI's Standards of Excellence visit us online at www.nami.org/standardssofexcellence.

The NAMI HelpLine is a Life Line

By Maggie Scheie-Lurie

Thank you very much for responding to my e-mail. It helped to reassure me that I am not alone and that many, many others are experiencing these feelings of helplessness. I'll follow up on the resources you have offered.

—HelpLine Caller



The NAMI HelpLine bustles with activity these days. The phones are ringing: A young man is discouraged because his recovery is up and down. A sibling caregiver “at wit’s end” needs a support group. Someone requests information on emergency housing. These callers are typical of the thousands who contact the HelpLine each month seeking

mental illness recovery information. Knowledgeable HelpLine staff and volunteers deliver appropriate aid with understanding and empathy.

Letters and e-mails from around the country receive thoughtful written responses. Many requests require special skills to answer: volunteer attorneys respond to the hundreds of people a month who need legal assistance, such as the parent of a jail inmate diagnosed with a mental illness who is not receiving treatment. Each month a Spanish-speaking staff member handles 100 Spanish calls and letters and the HelpLine processes thousands of e-mails sent to the NAMI website.

Callers often express appreciation for the help they receive:

Bless you! Thank you so much for getting this information to me. This is invaluable informa-

(cont. page 8)

The 18-year-old Living with Mental Illness: Should You File for Guardianship?

By Ann Butenhof



Ever since birth or adoption, you have been taking your child to medical appointments, consulting with professionals, advocating for appropriate educational supports, assisting your child with handling funds and generally helping your child find his or her own way in society. In most states, individuals who reach the age of 18

years are deemed to be adults and thus the parents, without written authorization, no longer have the legal authority to speak with their children's doctors about medical treatment or to work with the school system on their behalf. An 18-year-old child might be high-functioning and thus able to act independently in most arenas, or they might need assistance with virtually all decisions that must be made in the future. Depending on where your child falls in this continuum, you may wish to consider filing for guardianship (or "conservatorship" in some states) in order to continue assisting your child with daily decision-making.

Guardianship is a legal process whereby a court is called on to determine whether an individual lacks the mental capacity to make certain decisions for him or herself. If the court deems that the individual lacks such capacity, the court then may appoint another person to make those decisions on behalf of the incapacitated individual. The individual over whom guardianship is sought generally is referred to as the "ward;" the individual to whom decision making authority is granted is generally referred to as the "guardian." By granting decision-making authority to a guardian, the court takes such authority away from the ward.

In a guardianship action, the proposed guardian can seek authority (a) to handle the ward's assets and to make financial decisions (*i.e.*, guardianship over the "estate"), (b) to make life decisions that are not financial in nature, such as educational and health care decisions (*i.e.*, guardianship over the "person") or (c) to have authority to handle all the above on the ward's behalf. When bringing an

action for guardianship, factual allegations relating to the proposed ward's alleged incapacity to engage in specific activities or decision-making must be proven in court. In granting guardianship, the court can issue an order granting broad authority to a guardian—essentially enabling the guardian to make any and all decisions—or it can issue an order granting the guardian very narrow authority, such as the authority to manage the ward's financial accounts. Moreover, the guardianship can be granted on a short- or long-term basis. In theory, the court should narrowly tailor a guardianship order to the particular ward.

Although the level of proof necessary to obtain guardianship varies from state to state, the burden of proof that a guardianship is warranted and necessary rests entirely upon the individual bringing the petition for guardianship. The proposed ward is entitled to be represented by an attorney and has the right to object to the petition. It is important to recognize, therefore, that a court will not grant guardianship simply because a parent requests it and claims it would be in the child's best interests. Rather, the parent must be prepared to produce evidence to support the claim that guardianship is necessary.

The statutory or common law basis for defining when guardianship is warranted will vary from one state to another. In general, the court will be asked to determine whether the proposed ward is capable of providing for his or her own basic needs (*i.e.*, food, clothing, shelter, health care or safety) and isolated instances of poor judgment or neglect should be insufficient to justify the granting of guardianship. If there are less restrictive measures by which the proposed ward can be protected (for instance, the signing of a power of attorney document for educational or financial decisions or a HIPAA release for review of medical records), a court should consider those options rather than imposing guardianship.

Once guardianship is granted, the guardian should anticipate having to file regular reports with the court, generally on an annual basis. The ward retains the right, which may be exercised at any time, to ask the court to end or further limit the guardianship in order to regain his or her right to make any or all decisions.

NAMI 2010 National Convention

Recovery and Reform: The Road From Here

NAMI invites you to join hundreds of fellow NAMI advocates on the road to recovery and reform. Scheduled for June 30–July 3 in Washington, D.C., our 2010 National Convention will examine the impact of health care reform on both politics and people, present up-to-the-minute information on advances in research and treatment that will aid people with mental illness progress on their journey to recovery, and give you a chance to meet face-to-face with your Congressional representatives. The convention will showcase dozens of projects underway throughout the United States to propel the NAMI movement forward as well as



feature some of the country's most astute thinkers and change agents. The convention is a time for learning, information-sharing, networking, and celebrating. We invite you to join us for this important—and joyous—event.

The 2010 National Convention will be held at the Hilton Washington, located in the heart of Dupont Circle, one of Washington's most vibrant neighborhoods. Hotel reservations can be made by calling (202) 483-3000 or online at www.hilton.com. To register for the convention—and get access to complete convention details—please visit www.nami.org/convention.

Army Troops in Iraq Hold 5K Run

Raise PTSD Awareness and End the Stigma around Mental Illness

An Army platoon in Iraq ran five kilometers (5K) in full body armor on April 17 to raise awareness about posttraumatic stress disorder (PTSD) and the need to end stigma surrounding mental illness.

Forward Operating Base Echo in ad-Diwaniyah, Iraq, held the event at the same time the National Alliance on Mental Illness (NAMI) affiliate in San Diego held a NAMIWalk at a more leisurely pace.

NAMI San Diego moved out Saturday at 8 a.m. (PT) while 3rd Platoon, Baker Company of the 3rd Infantry Division's 3rd Heavy Brigade Combat Team and others began the 5K run at 19:00 hours (Iraq time). "This is an incredible event," said NAMI National Executive Director Mike Fitzpatrick. "NAMI is honored that Army soldiers in a war zone have synchronized their commitment to public education with our San Diego affiliate."

"NAMIWalks across the country are about hope, recovery and community. They are fun events, but they support serious work."

"As the U.S. Army has taught me, not all wounds are visible," said Army specialist John Bell, who is organizing the Iraq event.

"As tough as a U.S. service member may be, many still suffer the effects of having endured life in a combat zone. The most prominent effect is

PTSD. Not every combat-deployed soldier has been in a firefight, or had their vehicle struck by an IED, or even lost a friend by an enemy engagement. But the trauma they endure is nonetheless significant to them."

- One in six veterans of Iraq and Afghanistan is affected by PTSD, depression or anxiety. Only about one-half seek treatment.
- One study has reported that 25 percent of Iraq veterans seen at veterans' hospitals receive mental health diagnoses.
- Approximately 40 percent of homeless veterans live with some form of mental illness.



For two years, NAMI San Diego development and events manager, Annie Dunlop told Bell, a friend, about NAMIWalks. Deployed in Iraq, he was unable to participate. This year he didn't want to miss out. The 5K will honor NAMI San Diego's work and NAMI efforts to help veterans nationwide through its on-line Veterans Resource Center and other programs.

Leadership Alliance Corner

NAMI and the family and friends who benefit from its programs would like to thank the 2009 donors of the Leadership Alliance for their thoughtful contributions. Thanks to their generous support education, recovery, and hope have been made available to those whose lives are affected by mental illness.

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The Dental Voice continued from page 1

can recommend over-the-counter remedies that supply emollients to the dry tissues and reduce decay. We would not suggest water for dry chapped hands, right?

This project will benefit the world of mental health in many ways. Awareness of dental care for mental health clients will be put at the forefront for total care. Instead of mental health care professionals feeling helpless concerning oral care, they will

be given tools to help prevent more tooth destruction and improve the quality of their patient's life. I have the passion and education—and hope you will join me in helping our community become more aware of this problem.

Lisa Knapp Stillman
Integrative Healing Consultants
Lisa91156@aol.com

NAMI HelpLine continued from page 3

tion for someone in my son's situation. When I first started looking for help, I didn't think there was much out there. I'm so glad I contacted you all. Again, thank you so much for doing this for me—and him.

—HelpLine Caller

All told, the HelpLine fields 80,000 requests each year, twice what it received 20 years ago. Staff also steps up to the plate when special projects come along, such as notifying NAMI affiliates about important news and leadership information that supports their local efforts.

Just who is answering all these calls and what motivates them? Many are family members or people in recovery. Some say they want to give back to others after living through their own struggles with mental illness. The HelpLine has also become an attractive internship opportu-



Douglas Bradley

nity for college psychology students. They learn first-hand about helping people living with mental illness while preparing for future careers.

Thank you very much! I thought I'd never get answers because no one understood me. I've been afraid I'd attempt suicide or hurt myself again. It gives me relief to know I'm not the only one going through this! I'll keep up with my social worker appointments and focus on doing good in my college courses. I'm glad you were there.

—HelpLine Caller

The NAMI HelpLine is the only national phone line of its kind, and without a doubt it serves an unmet need for tens of thousands of Americans. While our callers are very grateful to us, we are equally grateful to all who make the HelpLine possible. Thank you for your continued support.

NAMI HelpLine: 1-800-950-NAMI (6264)

Share Your Story

Your stories of hope and recovery from mental illness can help others in similar situations. Please send yours to Darcy Taylor at DarcyT@NAMI.org and have it published in upcoming editions of *NAMI Voice*.

I want to make a difference
for people living with mental illness.

NAMI.org makes a difference
to me
with
the latest research,
state and federal advocacy
and
community connections.

If you have any ideas or feedback on *NAMI Voice*,
please send them to Darcy Taylor at DarcyT@NAMI.org.