



## Board Message—Current Events

KSCO radio show *Body Mind and Spirit* interviewed one of our NAMI members this month. The show focused on the family story and beautifully brought to light the struggle that families go through with a loved one who has a serious brain disorder.

### CIT (Crisis Intervention Training).

The first 15 officers from the City of Santa Cruz, Capitola, Watsonville and the County Sheriffs Department completed their training last fall. Two CIT academies will be conducted this year with the goal of training all police officers working within the County of Santa Cruz. To volunteer and share your story as a family member for the NAMI CIT panel, call Judy Williams at 688-3385.



**NAMI-SCC hopes to begin the NAMI Family-to-Family Education Program late this spring.** It is free education and support for families who have relatives with brain disorders (severe mental illness). If you are

interested in learning more about Family-to-Family call us at 427-8020.

**Dr. Charles Torrey, the new Medical Director for Santa Cruz County Mental Health, spoke to us at our February Speaker Meeting.** Dr. Torrey spoke to a full house about the Village Concept which is a very successful program in southern California for mental health clients. It emphasizes the village, employment, housing, and provides career services and social involvement.

**Residents within the unincorporated areas of Santa Cruz County overwhelmingly passed Measure L.** The repeal of the utility tax will leave County Mental Health programs almost one million dollars short annually in the coming years. 🍷

## The President, Congress and The Mental Health Parity Amendment

### *Let's Hold The Leaders Who Killed It Accountable*

*Statement of Richard C. Birkel Ph.D., Executive Director, National Alliance for the Mentally Ill*

Late Tuesday, December 18, a conference committee of the U.S. Senate and House of Representatives voted to drop the mental health parity amendment from the Labor-HHS-Education appropriations bill (H.R. 3061). Key House leaders remained opposed to the provision until the end. Killing the amendment was more than a disappointment to individuals with mental illnesses and their families. It is an outrage, representing a conscious decision to protect unconscionable discrimination.

Mental illnesses are brain disorders. They are as much physical illnesses as heart disease,

*Continued Page 6*

## Questionnaire Results

The questionnaire results are in. Thank you to all who took the time to send us your experiences and recommendations concerning Dominican Behavioral Health and their interaction with families.

The results of the survey were varied with half responding that a crisis worker contacted them while their family member entered the hospital. The majority of the responses were about the lack of communication between the staff and family. One family member wrote "I would like to be treated as a member of the team concerned with a long-term helping relationship to maintain/improve the consumer's well-being." This statement was similarly echoed throughout the other questionnaires.

It is very clear that families feel the need to stay connected to their loved one. We will meet with the staff at Dominican to make recommendations concerning the inclusion of families and provide printed material for Dominican staff to distribute to families in crisis.

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## Mission

NAMI-SCC is a movement of families, friends and individuals dedicated to improving the quality of life for people affected by serious mental illness. NAMI-SCC provides support, education, advocacy and promotes research.

# Breath of Fresh Air

## Spirituality, Meaning and Recovery from Serious Brain Disorder

By Garth House

“...the alleviation of symptoms does not address the devastation and chaos the illness has wrought in the patient's life...”

**There are 10 NAMI FACT SHEETS that can provide disorder-specific help for families with children. They are free of charge from the NAMI HelpLine (1-800/950-6264), or from the NAMI Web site ([www.NAMI.org/youth/brochures](http://www.NAMI.org/youth/brochures)).**

Recovery from a serious brain disorder (mental illness), like recovery from any catastrophic illness, presents a great challenge to the human spirit. So shattering to the human personality are neurobiological disorders, so intense and comprehensive the suffering they involve, so total their attack on every aspect of the sufferer's life, that the deepest questions of the human condition are raised in the mystery and meaning of suffering, the search for faith and trust wherewith to confront it, and the question of destiny itself. It is therefore not inappropriate to speak of recovery from such illnesses in terms of a spiritual process. This is not to say that a serious brain disorder implies a spiritual malaise that requires a spiritual or religious remedy. Serious brain disorders are medical illnesses that require medical interventions to alleviate symptoms. But the alleviation of symptoms does not address the devastation and chaos the illness has wrought in the patient's life, the disruption to the lifestyle and to career, the loss of friends, the social isolation or the stigma associated with the illness. Neither does the alleviation of symptoms erase the indelible memories and deep resonance that the patient continues to carry of the content of those symptoms—the hallucinations, the delusions, the powerful, seductive and disturbing poetry of psychosis. These can make up an entire universe of experience that arises before the recovering person like a great unanswered question, a question that begs to be answered out of the very human longing to find meaning in experience.

The revolution in knowledge of the brain and of the biological basis of brain disorders over the past 30 years left little doubt as to the medical nature of these illnesses. Centuries of misunderstanding and ignorance as to the true nature of mental illness have been relegated to the dust bin of cultural history by these scientific break-throughs. But if the etiology, and most certainly the treatment, of brain disorders is now known to be a medical, scientific challenge, the broader question of a life-long process of recovery from the trauma of a brain disorder raises issues less narrowly medical and scientific and more broadly spiritual, where this latter term is understood both in the practical

tasks of rebuilding a disrupted life and in the deeper questions of the integration of suffering and experience outside the parameters of the “normal” into a meaningful world view. Essentially this is nothing less than the challenge of the human condition itself, from which no mortal is exempt, and which persons with serious brain disorders are both driven and privileged by their illness to meet with an immediacy born of circumstance.

If the distinction between the medical treatment of brain disorders to alleviate symptoms and restore psychiatric balance and the broader process of recovery from the trauma of these disorders is not drawn or is blurred, there is the risk that movement towards a full, meaningful life defined beyond the limitations of the illness itself will not take place. What then occurs is a sort of “biochemical hypochondria”, where the individual with the brain disorder embarks on an endless quest for the right combination of medications to set right problems of happiness, meaning, and fulfillment which are properly the fruit, not of the right mix of medications, but of the hard work of the spirit.

That suffering can be meaningful and even redemptive is an insight common to the spiritual traditions of the West. This is not to say that suffering is good in itself, or that it should be sought out for moral or spiritual improvement. But when affliction strikes and can't be avoided, from a spiritual point of view it can be seen as the occasion and opportunity for growth. That serious mental illness can be a growth process and an opportunity for the forging of important qualities like patience, endurance, faith and courage, is a radical understanding of what many regard as a completely deleterious and destructive pathology. But for the sufferer a therapeutic approach to serious brain disorders that affirms the importance and authenticity of his or her struggle, that acknowledges in the midst of the chaos and pain of the person's illness the presence of meaning and the operation of a spiritual power working towards re-creation and restoration and healing, for the sufferer such a therapeutic approach grants him or her the dignity worthy

of a struggle that in its extremity goes to the heart of the human condition.


A narrow medical model for understanding the phenomenon of neurobiological disorders, while it is important for addressing the treatment of symptoms, is not only inadequate for the broader process of recovery, but in fact it runs the risk of trivializing the sufferer's struggle. Hallucinations, voices, visions, convictions that one is an historical or religious figure for the person who suffers these experiences to be told it is all a matter of chemical reactions in the brain and nothing more is tantamount to declaring the person is "just plain crazy." The fact is that such symptoms leave a powerful imprint in the sufferer's imagination. They resonate with a power and significance that is equal to and sometimes greater than the weight carried by "normal" experience. There is a need, therefore, as there is with all life experience, for the person with a brain disorder to integrate such experience, at some point in the recovery process, into a meaningful worldview.

Of course, the task of integrating experiences outside the range of "normal" consciousness is not without peril and risk. Because the suffering of these illnesses is so extreme, suffering falls so far outside the range of ordinary comprehension, the terrain whereon recovery begins to take place once symptoms have been addressed is in itself inflationary and vulnerable to interpretations that are themselves distorted and off center. The 'dark' experiences of clinical and psychotic depression and the wild euphoria of psychotic mania make it

difficult for the recovering person who is attempting to make sense of such experience to arrive at a sense of identity and purpose that is marked by the proper measure of humility, integrity, and humanity.

Here is where the great religious and spiritual traditions can play a vital role, and where the psychiatrist, counselor, and pastor can assist and guide the recovering person as they integrate and heal the deep wounds of their illness. These traditions, and the overarching Spirit of goodness, mercy and healing to which they point, are broad enough to encompass the extremes that are experienced in serious brain disorders. A loving and accepting congregation of faith can restore to the recovering person, through its embrace, a proper and healthy perspective which affirms both the "chosenness" of that person for a special "way" marked by the unique extremes of mental suffering and yet at the same time embraces that person in their humanity as a human being worthy of love, healing, and community.

Thus it is that one of the most common characteristics of persons with serious brain disorders—religious preoccupation, obsessions, and delusion—can, if approached with medical expertise and spiritual insight and affirmed as an indicator of authentic spiritual struggle, provide a fertile ground for the growth and development of mature, vital deep and healing faith.

*This essay is by Garth House, a staff member of NAMI/Ohio, a veteran of serious mental illness, and the author of two books, *Litanies For All Occasions and More Litanies For All Occasions* (both Judson Press) *

**Front Street Residential Care:** A 47-bed residential care facility located between Downtown Santa Cruz and the Santa Cruz Wharf. 126 Front Street. Santa Cruz CA 95060, 831-427-3387. Administrator: Adrian Bravo.

**Front Street Day Rehabilitation Program:** A day program providing therapeutic activities designed to help individuals attain their highest goals and live in the least restrictive setting.

**Opal Cliff Rehabilitation Center:** A 15-resident long-term residential psycho-social treatment program designed to help residents gain life skills and reach individual goals.

**Darwin House:** A 15-resident long-term residential psycho-social treatment program designed to empower and help residents gain life skills and reach individual goals.

**WRC (Adult Residential Care Facility) WRC (Residential Care Facility for the Elderly):** 34 adult and 6 Elder-care residents in a beautiful, serene setting in the redwoods fronting Manson Creek.

**Willowbrook Intensive Treatment Program:** A multi-disciplinary program serving residents of Willowbrook residential facilities.

**Front St., Inc. Supported Housing:** Supported housing for 11 individuals in various locations.



**"A Circle of Caring: The Church and the Mentally Ill"** is an education series offered by Interfaith Compeer through area churches. Each session has a guest speaker, a video and printed material for participants to take home. If you are interested in finding out more about Interfaith Compeer please call Nancy Karges at 459-6817.

**Don't forget!**  
When you call 911, ask for a Crisis Intervention Trained (CIT) Police Officer.

**Front St. Inc.** currently provides housing for 128 individuals with severe mental illness in Santa Cruz County.



His shorts were a bright plaid, glaringly different from the pattern on his shirt. On his feet he wore red sneakers. On the self-consciously earth-toned Princeton campus of 1976, he stood out.

"Who's that?" I asked my friends in the math department about the odd-looking figure who hung around the math area, which faced the biology lab where I'd begun working on my doctorate.

"Oh, that's Nash," came the reply.

"Who's he?" I persevered.

"He's crazy, but he won't hurt you." End of discussion.

That was my introduction to math genius John Nash – years before he was awarded his Nobel prize in economics, years before his recovery from schizophrenia, years before the release of the film version of his biography, "A Beautiful Mind," which is scheduled to arrive in theaters in January. And years before I began to care about the stigma of mental illness.

I didn't question my friends' dismissiveness. Nash's illness reduced him to insignificance for me, as it did for so many others.

Like them, I grew accustomed to seeing "The Ghost of Fine Hall," as he was known, in and around the math department where he had been a fixture for years – a department in which he no longer had any formal affiliation but where all knew of his former glory. Outside Princeton, many academics assumed he was dead.

The trouble was that I saw this dead man walking everywhere on campus. He could hardly be missed. Hunch-shouldered, arms hanging, he wandered the grounds wearing a vacant expression and the same mismatched plaids in all weather, regardless of season. He muttered to himself and made no eye contact. His appearance was so unsettling that I never said hello or bothered with a half-smile. I never wondered who he really was beneath the off-putting exterior, why he was there, whether he had a family, what his background was. I simply tried to steer clear.

It took me 20 years to realize that in writing him off as almost subhuman, I'd fallen into the smug ignorance of most Americans. Sixty percent of them, according to one comprehensive national survey, want to distance themselves from people with schizophrenia. As a grad student in the 1970s, I was, as they say, part of the problem.

I came to Washington in 1982 to become a health policy worker and later became an independent medical writer. The topic of mental health did not reach my professional radar until 1998, when I was tapped to help draft and edit the first-ever surgeon general's report on mental health.

The project began with a call from the project's senior scientific editor, University of Maryland psychiatry professor Howard H. Goldman. This report, he told me, was a watershed event. Never before had a surgeon general focused on mental health and mental illness. The current surgeon general, David Satcher, saw the document as an opportunity to draw attention to illnesses that were as real and disabling as heart disease and cancer but had rarely been treated as such. Would I be interested?

I hedged, not eager to commit to a topic of marginal interest. Even after I reluctantly agreed, I had no way of knowing how absorbing the assignment would become.

I began by editing chapters from experts. One part, "Outcome of Schizophrenia," explained that popular assumptions about schizophrenia – including that it follows an inevitable downhill course to total dysfunction – were based on a century-old description. Newer research that systematically

tracked patients over decades found that half to two-thirds of people with schizophrenia improve or recover. Schizophrenia was not a life sentence, especially with treatment, rehabilitation and support from family and friends. In fact, the expert wrote, "some people with schizophrenia can experience a remission of their symptoms and return to a high level of functioning." That was news to me.

To illustrate the point, the author cited the story of a certain John Nash, the 1994 Nobel prize winner in economics. I re-read this descriptor with astonishment, wondering briefly if this could possibly be the same figure I recalled from graduate school days. I then pushed the question from my mind. But a few weeks later, curious to know more, I bought Sylvia Nasar's 1998 biography of the troubled genius. As I leafed through the book, I came upon a picture of Nash from Princeton – which had been taken while I had been there in the 1970s. In black and white, there was the indelible image: Nash wearing mismatched plaids, that same hollow stare in his eyes.

His biography transported me back to the Ivy League campus – and back even further to the history of its illustrious math department. In 1950 Nash earned his doctorate there in a branch of mathematics known as game theory, a system for assessing competing strategies and outcomes in such areas as economics, political science and sociology. It was his work in this field that, more than 40 years later and long after his terrible battle with schizophrenia, would win him the Nobel prize.

In graduate school, I remembered, I had spent nights over wine and beer with math students, watching them crack jokes and scrawl unfathomable equations on napkins. I recalled their awkwardness, their crooked glasses, greasy hair and body odor. Yet the biography made clear that even within the quirky and cloistered world of the math department, Nash was a loner. He was withdrawn and inaccessible even before the onset of his mental illness.

But, as Nash's biography relates, it wasn't until after he left Princeton for his first faculty post at the Massachusetts Institute of Technology (MIT) that he began a precipitous mental slide. In 1959, when he gave a lecture to the American Mathematical Society, Nash rambled incoherently. To listeners, the lecture seemed to certify him, in the most conspicuous way, as a madman.

## Mental Health C

As a Patients' Rights Advocate, I am profoundly and adversely affected by mental illness daily. This stigmatized society places upon others the burden of distance themselves from those who are different. This is often accomplished through stigmatization like "crazy person," "nut

For a vast majority of people, stigmatization is driven by the fear of "losing" one's own sense of self. The illusion of creating a safe space at large believes it needs to protect both to those who are stigmatized as well as those who have mental illness. Wellness exists on a continuum in each individual. Therefore, it is damaging for those who are "normal" to constantly be

For those stigmatized and not seen as individuals, the stigma ties. For those who have mental illness but could benefit from treatment, the stigma increases the likelihood of being sought. For those who have mental illness, the effects are worsened because psychosis is made worse by the lack of gentle or non-competitive

The worst effect of stigmatization is that it makes themselves "normal" and has been diagnosed. In the process of the sterilization of the "merely" overly restrictive legislation against the right of the neighborhood.

I maintain that in this world of the closet about one's mental health, the one is bi-polar. If you are fearful of the shame of taking those first steps to treatment, it is painful, but you must have the knowledge that you are reaching out to those who are struggling and to society.

If you are fearful of becoming educated about mental health, you can do that. You can do that to support people with mental health. Health Client Action Network

## Nobel Prize Winner, She Behaved Badly. She's Beginning to Understand Why.

Nash's wife made the painful decision to have him committed to McLean Hospital outside Boston. Psychiatrists diagnosed paranoid schizophrenia. So on a 30-year nightmare of delusions, hallucinations and disorganized

thoughts and speech – the hallmarks of one of the most feared mental disorders.

Many of the treatments he received have long since been discredited. In 1961 doctors at a Princeton-area hospital subjected him to six weeks of insulin coma therapy – daily injections that sent his blood sugar plummeting and rendered him comatose, followed by forced feedings of glucose to revive him. Recoiling at what he called being "tortured," Nash would drop even apparently effective medications upon discharge, prompting a new cycle of troubles and treatments.

In 1960, convinced he was a political prisoner, Nash traveled to Europe, determined to hand in his passport at a U.S. embassy. Initially he was talked out of it; later he simply threw the document away.

I expected little more than a good read from Nash's biography; what I got was a lesson about the shattering impact of schizophrenia. But I didn't stop to think about my own behavior toward Nash until I got to the account of the battle over his nomination for the Nobel prize.

The Royal Swedish Academy of Sciences awards the Nobel prizes after secret negotiations by several committees. But what happened to Nash was such an indictment of the participants that some later felt compelled to reveal the story.

When Nash's candidacy was first considered in the late 1980s, the selection committee immediately expressed concern about incurring embarrassment if they awarded the prize to someone with schizophrenia, even though Nash's work in game theory was finished in 1951, several years before the onset of his illness.

The committee dispatched a scout to Princeton with one mission: to determine whether the rumors that Nash was recovering were true. Nash was eccentric, the member reported back, but no longer crazy. His recovery had begun gradually in

The committee proceeded with Nash's application, but not without resistance. One member claimed to be skeptical of the value of Nash's work on game theory, despite the fact that it was already being applied on an international scale in commerce and diplomacy. When the nomination came before the full body for a vote, Nash was awarded the Nobel prize in one of the closest votes in the Academy's history. Debate was so bitter that it delayed the usually punctual news conference to announce the winners.

After reading this, I realized that if members of the Academy – so educated, so worldly, so refined – could so nearly let a personal history of mental illness blind them to an individual's accomplishments, then others could, too. Including me. Even if my long-ago reaction to Nash was instinctive, unlike the committee's prolonged consideration, it was no less disturbing, no less a violation of a person's worth.

Why had I thought only of avoiding Nash when I passed him years before? Why had I reacted with revulsion, not empathy? Why had I not stood up to those who ridiculed him, who dismissed him as a freak?

These thoughts became enmeshed in my writing of the 1999 surgeon general's report.

Stigma, I wrote, is *"the most formidable obstacle to future progress in the arena of mental illness and health... It is manifested by bias, distrust, stereotyping, fear, embarrassment, anger and/or avoidance.*

*"Stigma leads others to avoid living, socializing or working with, renting to, or employing people with mental disorders, especially severe disorders such as schizophrenia... It reduces patients' access to resources and opportunities (e.g., housing, jobs) and leads to low self-esteem, isolation and hopelessness. It deters the public from seeking, and wanting to pay for, care. In its most overt and egregious form, stigma results in outright discrimination and abuse. More tragically, it deprives people of their dignity and interferes with their full participation in society."*

It's right there in print. Little did anyone know I was at that point writing a kind of self-critical autobiography. But still, no dogmatic report can translate realizations into personal behavior.

As passionate as I've become about the plight of mental illness, I'm no Mother Teresa. I do not now run over and greet wild-eyed strangers I see on the street; they still make me uneasy. But now I am willing to pay slightly higher taxes or insurance premiums if that's what's needed to get them adequate psychiatric care – far more humane and effective these days than what Nash experienced. And I know now their humanity is inextricably connected with mine.

As I was writing the section of the surgeon general's report dealing with the consequences of stigma, I felt almost as though I were shaking myself free of a lifelong hangover. Even if my insensitivity toward Nash made no difference to him at the time, it had tacitly endorsed others' disregard of him and condoned a kind of social injustice.

Gradually, my ignorance and apathy about mental illness evolved into empathy. But that transformation did not occur solely by educating myself. It took Nash's story to rouse me. It took recognizing that I was part of the problem. I'm still working on it.

*Freelance medical writer Miriam Davis is working with co-author Howard H. Goldman on a book about the stigma of mental illness. Miriam Davis Special to The Washington Post December 18, 2001; Page F1*

by George Carvalho

people whose lives are shaped by the stigma of mental illness that individuals in the mental health issues community are intuitively from them. The use of derogatory labels like "wacko."

In a population this stigmatized as well as a deep alienation may produce the distance society. In reality, it is alienating. Psychiatrically diagnosed illness and mental health in our society and with a faint demarcation. They themselves to be

on results. People are defined by general psychiatrically diagnosed fear of isolation. Health services will not psychiatrically diagnose. The terror of psychiatric isolation and sudden contact.

that some who label against those who have in the form of forced today fear is evident in organized demonstrations to live in one's neigh-

It is easier to come out of isolation than it is to say it from treatment but finding the courage to living with stigmatization the experience and it can bring healing to overcoming fear and mental illness.

and with mental illness, mental illness and mentoring in organizations such as Mental Health Affiliates of NAMI.

1980s – no one knows precisely why or how. But the key ingredients, in his biographer's view, were likely the gentle support of his wife and the sheltered Princeton campus. One day, the story goes, Nash suddenly turned to a professor whom he'd never spoken before and remarked that he'd seen the man's mother quoted in the newspaper.

## Family and Consumer On-Going Support Groups

### Mondays

**On-going Smoking Cessation Groups (education class)**  
300 Harvey West Blvd., Santa Cruz Connection  
12-12:45 PM 425-8132 or 1-800-NO-BUTTS

### Tuesdays

**Schizophrenia Support Group**  
1051 Cayuga, Santa Cruz, MHCAN  
1:30-2:30 PM 469-0462 or 476-8474

**Women's Support Group** *Peer facilitators: Martha and Lisa*  
1051 Cayuga, Santa Cruz, MHCAN  
12:00-1:00 PM 469-0462

### Wednesdays

**Mood Matters (Support for those with mood disorders)**  
1051 Cayuga, Santa Cruz, MHCAN  
7 - 9 PM 469-0462

### Thursdays

**NAMI SCC Coping Group**  
(Support for family members)  
300 Harvey West Blvd. Community Connection  
7-8:30 PM 427-8020

**Parents of Teenage Alcoholics**  
(Support group-ALANON) 4951 Soquel Drive, Soquel  
Congregational Church of Soquel  
7:30 PM 462-1818

**Obsessive Compulsive Disorders Anonymous**  
A support group for OCD sufferers, their family and friends.  
1215 Mission Street, Santa Cruz  
Not meeting currently but you can call for support 438-1043

**Men's Support Group**  
1051 Cayuga, Santa Cruz, MHCAN  
1:00-2:00 PM 469-0462

### Weekdays

**Mental Health Client Action Network (MHCAN)**  
Coffee, resources, peer support, safety) 1051 Cayuga, Santa Cruz,  
MHCAN Monday, Tuesday, Thursday, and Friday 9-3 PM, Saturday  
12-3 PM. Closed on Wednesdays 469-0462

*The President, Congress and The Mental Health Parity Amendment, continued from page 1.*

diabetes, or epilepsy. Congress should not be abandoning the millions of Americans who battle severe mental illnesses every year.

A small group of House leaders instead chose to ignore the will of the majority. People cannot help but wonder whose interests they served. Certainly not those of American families. Certainly not those of children. And certainly not those of other Members of Congress who have wanted to do the right thing.

Since 1995, the House of Representatives has not held a single hearing on parity, in spite of the Senate's hearings, deliberations, and action. Some of the House leaders who have worked so hard to block the Senate parity amendment to H.R. 3061 are in fact the same leaders who have refused to hold hearings.

Members of Congress already have health insurance providing parity for mental health benefits. So do other federal workers, including those who work at the White House. That is only right, but other Americans deserve the same protection.

NAMI is grateful for the bipartisan efforts of all those Members of Congress who have fought hard for parity. Senators Pete Domenici (R-NM) and Paul Wellstone (D-NM) have been the lead sponsors, supported by Senator Ted Kennedy (D-MA).

In the closing hours, President Bush remained our hope. He signed the Texas parity law in 1997. He too knows the pain that can result from untreated mental illness. He has the power to turn House leaders and the White House staff around on the issue. But the President did not act, and we are greatly disappointed. Our consolation comes in this promise: parity will not go away. If our leaders fail, we will hold them accountable every time a family faces a crisis or is plunged into grief. Every time insurance discrimination kills, we will ask them again: whom do they really represent?

We will be back. And next time, the majority will win. Stigmabusters are encouraged to thank those House members who voted for parity. 🗳️

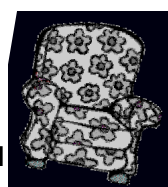
*Additional information and a complete copy of this letter, including how to contact specific members of Congress, go to NAMI's web site at [www.nami.org](http://www.nami.org).*

**Thank you  
for your  
generosity!**

NAMI-SCC thanks those who have generously donated to the Nate Evans Memorial Fund. Your contribution is greatly appreciated and will go towards

educational materials to help families.

We would also like to thank the generosity of PEETS TEA and COFFEE for donating coffee and condiments to the CIT training for Police officers. Peets is located in Downtown Santa Cruz next to Cinema 9.



### Can You Contribute?

*Your donations of furniture or other household goods are always needed for consumers moving into housing.*

*Please call Community Support Services and ask for Paul O'Brien at 459-0444.*

1. Families complain about staff who seem impatient, insensitive, unavailable, judgmental, condescending or patronizing. Many families report that they experience hostility from mental health professionals; others say that they are made to feel "invisible," and that their concerns are somehow considered illegitimate. Families particularly object to being "talked down to" by clinic administrators and psychiatrists. These attitudes make families feel humiliated, angry, defensive, confused and frustrated.
2. Families say professionals often make them feel blamed and stigmatized. Many professionals convey the message that the family has caused, or is continuing to generate illness in a family member. Mothers and wives are routinely perceived as "domineering," "rejecting," "intrusive," or "sabotaging" the treatment of their stricken family members. These attitudes make families feel guilty and ashamed. In response to stated family needs to find ways to restore connection, many professionals prescribe autonomy and independence as the "proper" posture for individuals with brain disorders. Families feel their good intentions appear suspect, and their forbearance and loyalty remain unnoticed.
3. Families of people with serious brain disorders object to traditional family therapy based on family systems theory, family "dysfunction" theory, communication deviance theory, etc. They complain that the therapy agenda has nothing to do with their own perceived needs for guidance and support. They feel enormous distress at being made to feel that they are "part of the problem," or that the ill family member's symptoms are "useful" in sustaining family dysfunction.
4. Families report that traditional family therapy often causes the ill family member to identify them as "perpetrators" and to turn against them. In this way family therapy colludes with the patient's denial of illness. This outcome can irreparably damage family relationships and compromise the family support system.
5. Families can't comprehend why some professionals seem blind to their pain, their genuine grief and their anxious worry about a gravely disabled family member. They say it is difficult to find a professional who offers

genuine comfort under such circumstances, or who understands the utter devastation that they feel. Professional insensitivity about their emotional distress adds to the family experience of isolation and rejection in times of crisis.

6. Above all, families feel ignored by professionals and left out of treatment planning. They are critical of how professionals refuse to communicate with them, are unavailable in times of crisis, and decline to give them vital information about the ill family member's condition which would help them understand and cope with the illness. Families relate how disturbing it is to seek information and support and be met with avoidance or recrimination. Families are particularly frustrated when professionals invoke confidentiality to avoid talking with them, or are inflexibly opposed to family collaboration, second opinions, and utilizing supportive resources outside the system.
7. Families often complain that mental health workers are not given specific training in a collaborative model of care, nor are they well-educated about the biological bases of mental illness and the residual illness behaviors families must cope with. It is exasperating for families to try to work with mental health professionals who cannot speak the language of serious brain disorders that families are intimately familiar with—symptoms, prodromal warning signs, relapse, physical exhaustion, lack of motivation, medications and side effects, treatment resistance and non-compliance. Families say that their reality and the professional attitudes of mental health workers are worlds apart, that it is almost impossible to communicate family needs in the absence of any kind of shared understanding.
8. Families worry that some professionals share society's disdain for people with brain disorders—that they too stereotype their clients and easily lose patience with them. Families express fear that if their family members don't conform the way the system wants them to, the system begins to retaliate and withdraw support. Families say that they fear reprisals if they criticize or protest clinic policies, and that they are often branded as "trouble-makers" when they express objections. 🗨️

## "What Hurts" Families of Individuals with Brain Disorders

### A Guide to What Families of Individuals with Serious Brain Disorders Need from Mental Health Professionals

By Joyce Burland, Ph.D.,  
Director NAMI Family-to-  
Family Education  
Program



### Can You Help?

Our phone tree service could make good use of an additional caller. It requires just a few minutes of your time once a month or less and can provide our members with opportunities for contacts that can turn out to be extraordinarily helpful. **If you would like to learn more about this service please contact Debbie Smith at 423-0845. If you would like to help with this newsletter call Judy at 688-3385.**

Psychiatric Emergency Phone Numbers:

- Adult Day (8-5; Mon.-Fri.) . . . . .(831)462-7644\*
- 24 hour . . . . .1-800-952-2335\*
- (during the day the 800# would get access team)
- Youth North County (24 hr.) . . . . .(831)425-0771
- South County (24 hr.) . . . . .(831)428-2226
- Children's Day (8-5; Mon-Fri) . . . . .(831)454-4900
- After hours call . . . . .(831)462-7644\*
- \*Dominican Hospital; adult 24 hour 800# goes to Dominican after hours)

Suicide Prevention Service

- 24 Hour . . . . .(831)458-5300
- 24 Hour Toll Free . . . . .(877)663-5433

Patients Rights Advocacy Program

- Santa Cruz (8-5; Mon-Fri) . . . . .(831)429-1913
- Watsonville (8-5; Mon-Fri) . . . . .(831)688-8833

NAMI-SCC Board of Directors:

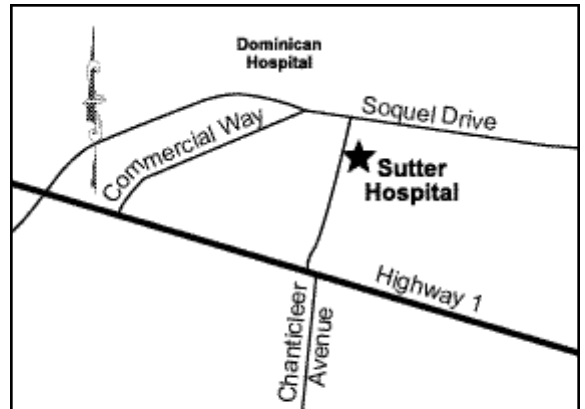
- Desiree Douville, President**  
douville@hotmail.com
- Betty Mitchel, Vice President**
- Judy Williams, Treasurer/Membership Chair**  
jujubees@cruzio.com
- Don Hilbert, Secretary**  
darhilb@got.net
- Louise Loots, Family to Family Education**  
louise@cruzio.com
- Doug Huskey, Website Webmaster**  
webmaster@namiscc.org
- Paul O'Brien, Nonprofit Advisor**  
Paul410s@yahoo.com

Friends:

- Sharron Cohen-Barry, Liason for Mental Health Resource Center**  
mhrc@santacruzcommunityconnection.com
- Nancy Karges, Interfaith Compeer**  
nancy@interfaithcompeer.org

NAMI-SCC Board Meetings:

2nd Monday of the Month. Time can vary. Open to anyone interested. Please join us.  
**Meetings are held at the Sutter Hospital Meeting Room, 4:30 PM**  
 2900 Chanticleer Ave,  
 Santa Cruz, California



**Yes, I would like to join NAMI-SCC!**

Make check payable to NAMI-SCC, PO Box 360, Santa Cruz, CA 95061. Your NAMI-SCC dues and donations pay for the NAMI California Connection, NAMI Advocate, NAMI-SCC Newsletter and help support NAMI-SCC.

- Family \$45     Individual \$35     Client (free)
- Patron \$50     Life Member \$500     Benefactor \$100
- Donation\$\_\_\_\_\_

**Dues and donations to NAMI-SCC are tax deductible.**

\_\_\_\_\_  
 Name

\_\_\_\_\_  
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 City State Zip

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 Phone

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 email

**We need your help. Please volunteer and call 427-8020 for more information.**



**NAMI-SCC**  
 P.O. Box 360  
 Santa Cruz, CA 95061  
 www.namiscc.org

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