

A 'gravely disabled' mental health care system State's broken process wastes money, chances, lives

By: Carol Smith
P-I Reporter

Liz Browning nudged open the unlocked door of her son's apartment in Seattle's Capitol Hill and recoiled at the floor blanketed with garbage — drifts of unopened bills, mounds of cigarette butts, rotting food and feces.

"Hello ... hello?" Her voice captured on a video taken in March sounds strained, wishing her 22-year-old son into view, and at the same time terrified of what she might find. "We brought you some food. ..."

She startled, as her son Marc loomed into the frame — tall, baby-faced handsome but disheveled, his long dark hair hanging in his face, a cigarette hole in the crotch of his drooping pants. He muttered to himself, and glared at the camera.

Browning felt sick from the stench. She forced herself to keep talking, trying to reach some part of him that remembered who he was before: Marc — the funny, sweet-natured scion of a prominent Seattle family and descen-



Liz and Marc Browning in Mental Health Court (in 5 point restraints) minutes before Marc was — once again — released back to the streets bare-foot — because of West Seattle Psychiatric Hospital's lax recordkeeping.

dant of legendary fire-arm inventor John M. Browning; Marc — the boy who once played Michael Darling in a Seattle Intiman Theatre production of "Peter Pan." That Marc had disappeared.

Mental illness is an insidious form of identity theft, erasing one future and replacing it with another.

But the state's mental health care system abets the crime. The Brownings, like thousands of other Washington families dealing with

mental illness, are snared in a Kafkaesque system that won't help people with serious symptoms until they are in imminent danger of harming themselves or others, or gravely disabled — standards so high they exclude many who desperately need help.

But this strategy ends up costing the public more money, and puts citizens at greater risk, a scenario tragically highlighted in this state by a string of high-profile slayings by people who had severe mental illness but could not be treated despite signs that they needed help.

How the state treats — or

fails to treat — its mentally ill is in the headlines again after Tuesday's bloody shooting spree, which left six dead. The family of Isaac Zamora — the man arrested in the Skagit County killings — has said the state didn't deal with his mental illness to help him and to protect the public.

It's not for lack of spending money that the state has failed. A Seattle P-I analysis found that the state spends at least \$1.8 billion a year directly and indirectly dealing with mental illness, or its aftermath. Of that money, \$530 million is spent directly on mental health care. The rest — \$7 out of every \$10 — goes toward prisons, police, homeless shelters and other social services that deal with the consequences of lack of treatment and preventive care.

This approach keeps people

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cycling through the streets, courts and jails. Beyond that, it squanders opportunities to intervene early on when there may be a better chance for successful treatment and recovery.

Ultimately, it wastes minds and costs lives.

The intruder

Liz Browning took in the bunker of her son’s illness. An upright vacuum lay toppled on a table. Shaving cream blotted part of the bathroom mirror, and glass from a broken window littered the floor. Electronic devices — a television, an iPhone and a computer — all smashed. It appeared that a frantic intruder had trashed the place.

Marc insisted to his parents that there were people shadowing him — people who vandalized his property and spoke to him in “voices you don’t want to hear.”

But Marc’s connection to reality had been spotty and fading for months. He started to lose himself in pieces. Strangers called his parents to tell them they’d found Marc’s phone buried in their yard. Other strangers found his wallet in the street. Occasionally he would show up on the veranda of his family’s gracious Capitol Hill home, ranting through the door until, feeling trapped, his mother called 911.

Now Browning stared into the face of the intruder. The invader had taken up residence in Marc’s mind. The invader’s name was schizophrenia.

A few months earlier, Marc had called for help. “I love you a lot,” he began in a voice message left on his parents’ phone: “If I could ask for one thing — if you could find me a good hospital ... I just can’t do it ... I’m not thinking right — everything is just going poorly for me. If I could just feel better, look to the future ... I feel so lost.”

Over the next three days, Browning and her son went to three hospitals — the University of Washington Medical Center, Harborview Medical Center and Swedish Medical Center — none of which would or could accept Marc because he wasn’t sick enough.

“You almost hope they are really, really bad,” Browning said. “And that’s just so wrong.”

Do not pass go

Hospitalizing someone for mental illness has morphed from a medical decision into a legal issue, said Dr. Peter Roy-Byrne, chief of psychiatry at Harborview. “It’s like if someone came into the ER with chest pain or cardiac arrhythmia, and we had to tell them, until they have a heart attack or need a heart transplant, we can’t do anything.”

Then when patients are sick enough to go to the hospital, they are often more difficult to treat. Or patients get stabilized just enough to be sent back to the community, where, without sufficient services and follow up, they fall apart again. In what becomes a malevolent sort of social Monopoly game, the players are constantly forfeiting their gains to start over — or go to jail.

For families, it’s a grim game with stakes that are too high. There’s a complex web of reasons for their frustrations.

Washington is one of the few states where neither families nor their doctors can decide that someone needs to be committed involuntarily for care. The only people who can make that petition are county-designated mental health professionals — government workers, who are not typically psychiatrists or clinical psychologists.

There are 28 such workers to handle crisis calls from a county with a population of 1.8 million,

a ratio that frustrates many clinicians who say that between the laws and the decision-making process, they are frequently unable to provide care, or are forced to release people when they are still in a precarious mental state.

Strict application of only the most severe criteria for commitment, coupled with a critical shortage of psychiatric hospital beds, prevents many people from being hospitalized when they might most benefit from it. Group housing with supervised treatment, scarce to begin with, is disappearing, limiting options for

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Peer Corps and the Seeds of Student Empowerment

by Caroline Kulczuga, student at Northwestern University,
Peer Corps Coordinator, NAMI Greater Chicago



Caroline

I first became acutely aware of the lack of mental health resources for college students in the spring of 2007. I became aware of the misinformation out there on mental illnesses. I also learned of my ability to do something about it.

My first two years of college were largely a personal journey. I was seeking to find and be comfortable with myself. Although I had heard stories of students experiencing trying times, not knowing where to look for help, and more, I had not really grasped the big picture. However, as time went on, I met more people, expanded my social networks, and was privileged to learn about many personal stories of hardship, triumph, and tragedy. I began to form an impression of what was truly going on in many university settings. The conclusion I reached—college-age students deal with an incredible array of mental, social, and physical issues. These include anxieties that are compounded by an unfamiliar new environment and the lack of information about the resources available to students. There are also many students disillusioned with the mental health system they encounter or flat-out do not believe that things can change for the better.

In spring 2007, I became an intern for NAMI Greater Chicago (NAMI-GC), and began to work almost exclusively on the NAMI Chicago *College Outreach Program* (NCCOP). I learned an incredible amount about mental health and why an adequate mental health system is such a critical component of college life. The vast majority of mental illnesses have onset during the college-age years. Yet despite its prevalence, the stigma of mental illness pervades almost every echelon of society. College-age students are the most likely age group to develop a mental illness and yet are often away from their traditional support networks, are uninformed, or afraid to ask for help.

To tackle this problem, Isabelle Burtan, NAMI-GC project director, and I developed the NCCOP initiative—*Peer Corps*. Based on a thirty-plus-year successful peer counseling program at Harvard University, *Peer Corps* is a student-run, peer counseling and training program. It can be implemented at

any university. Our program is rooted in two concepts—empathy and education.

The *Peer Corps* training model teaches non-judgmental and non-directive listening skills. Instead of being solution-oriented, we are trained to reflect students' emotions and to be with them in the moment. *Peer Corps* counselors do not give advice, diagnose, or pass judgment. They are well informed about the resources available on campus and in the surrounding community and are trained in referral skills. With this program, we hope to create a safer, healthier, more informed, and supportive campus community.

We work *with* the university mental health system and compliment its services—to allow more students to be helped and educated while also allowing them to take charge of their mental health to become more active and educated members of the community.

Through the incredible guidance of Isabelle, and a lot of hard work, *Peer Corps* is being launched at Northwestern University. Word about the program is spreading to other Chicago-area colleges and universities. We have a group of students at Northwestern who are trained in the program. The training model includes forty-plus hours of training. Implementation of the program has included conducting training sessions, holding supervisory meetings, developing budgets, developing materials, and contacting university administration.

Despite the immense work and commitment that has gone into launching this initiative, the most difficult part is gaining administrative support. In the wake of tragedies like Virginia Tech and Northern Illinois University, we believed that the need for programs like ours would be crystallized. But changing the system has been a challenge.

Nonetheless, the seeds of student empowerment have been planted, and the motivation and commitment of students is truly inspiring. I am a senior now, and will soon leave college life behind. Yet I leave confident in the strength of our peer-support message and in the knowledge that it is expanding and taking hold.

To learn more about *Peer Corps*, contact NAMI Greater Chicago at info@namigc.org.

Obama Administration and NAMI: Hitting the Ground Running

After only a few days in office, President Obama is already working with the new Congress to move aggressively on an agenda to revive the American economy and reform our nation's health care system. NAMI is working to influence these critical debates for our nation, to ensure that people living with serious mental illnesses and their families have a seat at the table and to ensure their needs are integrated into any legislation that emerges from Congress.

Health Care Reform in 2009

The President made health care reform a major part of his campaign for the White House last year. He will be pressing Congress for action on legislation to move our nation toward a universal system. Control costs and improve quality. NAMI enters this debate fresh from a historic victory in 2008 with enactment of the Wellstone-Domenici Mental Health Parity and Addiction Equity Act. The new federal parity law will ensure that mental illness and addiction treatment no longer second class status in any health care reform debate. Moving forward Congress will now abide by a principle that mental illness and addiction treatment are covered on the same terms and conditions as all other medical conditions.

Beyond parity are critical debates over addressing the uninsured, improving quality, advancing prevention, wellness and chronic disease management. Americans diagnosed with a mental illness make up nearly one-third of the uninsured population – in part because of the high unemployment and intermittent employment.

More importantly, individuals with serious mental illness have significantly higher rates of comorbid diseases such as diabetes, hypertension and chronic obstructive pulmonary disease (COPD). This is directly related to the relationship between serious mental illness and patterns such as high rates of substance abuse, smoking, poor diet, and lack of exercise.

In fact, a 2007 report from the National Association of State Mental Health Program Directors (NASMHPD) found that adults with serious mental illness have a life expectancy 25 years shorter than the general population. This report dramatically demonstrates why consumers and families have so much at stake in development of policies designed to promote chronic disease management, prevention and early intervention. NAMI welcomes this debate as an unprecedented opportunity to pursue

integration of primary care into psychiatric treatment through policies such as the “patient centered primary care,” electronic medical records and chronic disease management.

The President's Economic Recovery Agenda

The current economic down-turn is already having a devastating impact on state budgets and critical programs that meet the needs of people with mental illness and their families. Both children and adults living with serious mental illness rely heavily on public programs such as Medicaid and state and local mental health departments.

In response to the current economic crisis, Congress and the Obama Administration are now crafting an \$825 billion two-year package of public investments and tax cuts to promote recovery and stimulate an American economy now in recession. There are a number of provisions in this package of critical importance to children and adults living with mental illness and their families.

Central to this economic stimulus package is assistance to states to ensure that the current crisis and corresponding shortfall in state revenues do not result in further fraying of the already fragile safety net that children and adults with mental illness rely on. NAMI strongly supports the proposal for \$87 million in additional federal Medicaid matching funds for the states over the next two years to maintain eligibility for the program and prevent further cuts to community-based services such as pharmacy benefits and case management. In addition, NAMI also supports the current proposal for an additional monthly payment for all Supplemental Security Income (SSI) beneficiaries.

NAMI also applauds Congress and the President for including other critical investments in this economic recovery and stimulus package:

- \$2.5 billion for the National Institutes of Health (NIH) and the National Institute of Mental Health (NIMH), including funding to complete construction of the new John Porter Neuroscience Research Center,
- \$20 billion for development of Health Information Technology (IT), and
- \$2.5 billion for upgrading and retrofitting of existing supportive housing projects.

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people facing hospital discharge. Although community outpatient mental health programs exist, the majority of patients who end up in them eventually vanish from treatment.

Nearly two-thirds of people who used public mental health services at least once never returned, according to the state's Institute for Public Policy Research, which recently looked at compliance levels. In the lexicon of mental health workers, they are known as "leavers."

"We wouldn't let an Alzheimer's patient leave the hospital to go sit on a sidewalk grate and rot," Roy-Byrne said. "But we do that all the time for people who are mentally ill."

Jails as 'psych wards'

Between January, when he asked for help, and March, when the police finally put him into restraints and hauled him to West Seattle Psychiatric Hospital, Marc's prognosis darkened.

By then, whatever inclination he might initially have had to help himself had been subsumed by illness. On his admission, Marc told social workers he wanted to "get a restraining order against the police because they won't leave me alone."

According to hospital notes, he didn't seem aware of why he had been brought in. He was angry, his mood unstable, and he denied being sick. He refused antipsychotic medication, and the hospital by law couldn't force injections without an additional court order. Within days, Marc was out of control, attacking staff members during an altercation over his smoking privileges. Several orderlies had to forcibly restrain and sedate him.

Then they called the police.

On April 24, Browning waited behind a glass enclosure while her son, wearing an orange jail-house jumpsuit, was led into the

courtroom. He seemed oblivious to the seriousness of the occasion, or even why he was there.

Marc stared around the courtroom, and glimpsed his mother behind the glass. The judge dismissed the charges and ordered him to Western State Hospital to be re-evaluated for civil commitment. When the judge asked him if he had anything to say to the court, he said: "Why is my mother crying?"

Psychotic break

After the hearing, Browning stood on a street corner outside the jail still shaking with frustration. She had been operating on adrenalin for months as her attempts to get treatment for Marc verged into theater of the absurd. At every turn, either the law, or the disease, blocked her attempts to intervene.

On this day, her shoulders hunched forward, and fatigue pressed its thumbs under her eyes. Behind her, the giant image of a man somersaulting down a wall in perpetual freefall decorated the side of a county parking structure, an apt, if unintended, metaphor.

It felt, she said, like they were back where they started, only worse off. Now instead of a treatment plan, her son had a jail record.

"It's like I don't even know him anymore," she said.

Marc, the youngest of three children, was an unassuming, well-adjusted, happy kid growing up, said family and friends.

"He was sensitive and sweet with a natural charm and kindness," said his older sister, Ann.

Though he was smart, school was hard for him, and he drifted with little ambition, said one of his elementary school teachers.

In eighth grade, his parents sent him to a small private school for boys with dyslexia, but his problems continued. A year later, a school psychiatrist diagnosed him with bipolar disorder.

During his junior year in high

school, he was hospitalized for depression and suicide risk. Though he graduated and started college at Eastern Washington University, he dropped out in January 2005 — the middle of his freshman year — to go live with his older brother in Las Vegas.

One night, Marc began tearing apart the attic in the house he shared with his brother, looking for cameras he was convinced were tracking him. He accused his brother of controlling his thoughts. His parents persuaded him to go voluntarily to a hospital in Las Vegas for a week, then flew him back to Seattle.

But at home, his mental health continued to deteriorate, and in June 2005, a court committed him to a private psychiatric hospital. This time, Marc was uncooperative and tried to escape. The hospital wouldn't take him back.

So his parents did.

Marc's behavior grew increasingly erratic and frightening. He withdrew to his room for days at a time. Once, he slammed a chair through a window. His mother began locking herself into her own room at night, fearful of what he might do next.

In February 2006, the Brownings were able to get him committed on an involuntary basis, this time to Harborview Medical Center, where doctors diagnosed him with schizophrenia.

He was 20 years old.

For Liz Browning, her son's diagnosis confirmed a haunting heritage she had feared on some level since her children were young — a genetic loading the family couldn't escape.

A genetic bullet

On a recent morning, Browning hurried to meet her mother-in-law, Gloria Browning, at a Belltown cafe. They have much in common — both strong-willed and articulate, they also share a body of knowledge few

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of their friends comprehend. It's Gloria to whom Browning turns when she needs someone who understands how mental illness shape-shifts a life.

The cafe is just steps from where Gloria Browning lives in a luxury high-rise condominium, and also where many of the city's mentally ill wander the streets, untreated and unhinged. She rarely goes out in her neighborhood after nightfall.

This irony is not lost on Gloria, now the matriarch of her famous family, but she speaks unflinchingly about the Browning legacy. Browning inventions helped build the most widely used firearms of the 20th century — weapons that saw the nation through two world wars.

No gun John M. Browning designed, however, and no amount of wealth the family enjoyed, could defend against the genealogical bullet ricocheting through their family tree.

Gloria had six sons. Her eldest, namesake of his famous grandfather, leapt from the Golden Gate Bridge at age 27 after suffering for years with symptoms of schizophrenia and struggling to tolerate his medications.

He left a note saying he wished he could have lived.

A few years after his older brother's death, a second son shot himself. That son had struggled with addictions, including to anti-anxiety medications.

Now, two of Gloria's grandsons, including Marc, also struggle with mental disorders.

Gloria keeps track of advances in brain research and hopes for the day better treatments and earlier interventions let more of those with severe mental illness reclaim their lives.

The imposter

Liz Browning thought Marc had almost gotten his own life back.

After hospitalization at Harborview in the spring of 2006, he was released and lived for seven months at the Inn, a transitional group home in Seattle, which since has closed. There, he was supervised to make sure he took his medications, and soon, the witty and easygoing Marc re-emerged.

Encouraged, his family supported a move to his own apartment. He found one himself, outfitted it from Ikea and started back to school at Seattle Central Community College. He stayed on his antipsychotic medication, and paid his bills on time. His past few years began to seem a surreal detour.

But it's under this cloak of normalcy that mental illness lays its trap. People living with mind disorders start to believe that they no longer need the programs or medications that keep their thoughts in line, the voices at bay.

Within a year, Marc quit his medications. He stopped going to school. Quit paying his bills. Stopped making sense.

Because he had been out on his own, the mental health system had no mechanism for intervening, no way to break the freefall to come. Untreated, schizophrenia has its own kind of gravity, sucking its victims in like a black hole.

Even Marc could feel himself slipping. In January, he called his parents for help.

Browning saved the message, and plays it when she wants to make a point — to doctors, to lawyers, to mental health professionals — that the Marc they see — the hostile youth, the disoriented inmate, the uncooperative patient — that Marc is an imposter.

She plays it for herself.

Call back later

Liz Browning puts out a pot of tea for visitors on her back porch one recent sunny morning. She has a low threshold for small talk, and the conversation quickly turns to mental disorders.

If schizophrenia has seized her son's mind, it has also taken over her own life, consuming most of her time and energy. After the April assault charges, a mental health court ordered Marc to an involuntary commitment at Western State Hospital, where he remains today. His progress there has been slow, aggravated she feels by the long periods of time he spent off medications as he pinballed through the system.

Doctors confirm that it's harder to recover from each psychotic break.

"My greatest fear is the psychosis will be so damaging, we can't get him back at all — that he will be so ill, he's not really treatable," she said. "I might not know what I am fighting for."

She's helping to spearhead a movement to train more defense attorneys for work in mental health courts. She's advocating for the need to get commitments sooner. She's trying to organize an effort to create long-term care facilities where people with intractable mental illness can live together, work and have a decent quality of life.

But what she really wants, right at this moment, is to reach her son. She picks up the phone and dials the pay phone in the community room of his ward at Western State. A patient answers. She introduces herself and reminds the patient that she's met him, that she's Marc's mother, that Marc's the one who always wears a stocking cap. Could he tell him she's on the line?

Browning hangs on, the phone cradled against her shoulder. A few minutes pass. The patient never returns. Marc never picks up.

"I'll have to call back later," she says, to no one in particular.

This is what having your life hijacked by mental illness is like, being on perpetual hold.

Waiting to connect.

A Message from the Chief Operating Officer

For many years, NAMI members and leaders have been searching for ways to strengthen the NAMI movement. Members want NAMI to be a “household name” and a recognized and influential force in our communities.

Over time, we’ve come to realize that some of the power we seek will only come with greater mutual accountability *within* our own organization — we need to know what we can expect of one another and that we can count on each other. And, although “standards” might sound like constraints at first, we realize this is what it will take for us to grow and be strong.

We have sought members’ and leaders’ input and comments to develop NAMI *Standards of Excellence* as a way of establishing the basic expectations we in NAMI can have of one another. In keeping with the NAMI Strategic Plan and the desires of NAMI’s members and leaders as expressed through the Advisory Councils,¹ town hall conference calls, online surveys, and the guidance of the NAMI Standards Work Group², the NAMI Board of Directors has approved the first installation of those standards for gradual implementation.

Taken together, the practices describe the high quality of our organization and make the roles and responsibilities of the various levels of NAMI clear.

NAMI’s *Standards of Excellence* are intended to express a minimum baseline for what it takes “to be a NAMI.” The standards are:

- Guided by unifying visions
- Supported by required practices

On a sad note, I would like to take this opportunity to announce the retirement of Linda Radcliffe, the longtime Coordinator of our Leadership Alliance Program here at the NAMI National headquarters in Arlington, Virginia. Linda and her husband, Harry, are moving to the Atlanta area to be closer to their grandchildren. Please join me in thanking her for her many contributions to NAMI and our LAD family over her almost 8 years of service. Linda’s dedication, caring and kind heart, as well as her warm smile will be truly missed by all. We’d like to thank Linda for her dedication and service at NAMI and wish her well as she embarks on another phase of life’s wonderful journey.

Darcy Taylor
Director of Constituent Relations

- Extended by aspirations toward which all NAMIs are encouraged to work — these aspirations are the “stretch goals” that are above and beyond what we would hold as a minimum expectation, but a great goal for each of us to move toward.



Lynn Borton

We don’t impose these practices upon ourselves just because we want to, but because current and imminent legal requirements demand that we do so. Sarbanes-Oxley legislation, adjustments to the IRS Form 990, and other legal obligations of non-profit organizations *require* that we have standards — or we risk loss of our non-profit status, legal action, or loss of our credibility as advocates.

To view the first installment of the *Standards of Excellence*, as approved by the Board in December 2008, visit: www.nami.org/standardsofexcellence. Please join us in the discussion and in our efforts to grow and build a strong NAMI.

¹ NAMI’s Advisory Councils include: (1) National Consumer Council, (2) State Presidents Council, (3) National Veterans Council, and (4) Executive Directors Group.

² NAMI’s Standards Work Group is a representative, grassroots body of NAMI leaders from across the country that has been charged with developing organizational standards to help NAMI grow and be strong.

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At the same time, NAMI remains concerned about a proposal for \$1.1 billion for “comparative effectiveness research” (CER). While NAMI generally supports investment in research designed to improve health care quality and outcomes, there is growing concern that these CER studies are often misused as “cost effectiveness” studies that are used to deny coverage for specific treatments. NAMI supports CER, but with protections to ensure that these studies are not used by the government and other payors to deny access to specific treatment and therapies for individual patients and their families — especially for complex conditions such as serious mental illness.

NAMI Planning Blockbuster Convention to Celebrate 30TH Anniversary

JULY 6-9, 2009 • SAN FRANCISCO

NAMI'S 2009 National Convention scheduled for July 6-9 in San Francisco, will be a celebration of our 30 years of work to improve the lives of those who live with mental illness. Some of the highlights planned for this year's convention:

- A celebration of parity! NAMI's long years of work to achieve parity in insurance benefits resulted in the passage of the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 last October. Senator Wellstone's son, David, will join us for a special celebration, along with author Pete Earley (*Crazy: A Father's Search through America's Mental Health Madness*) talking about the power of advocacy to bring about change.
- Health and wellness will receive special attention this year, including a major presentation on metabolic syndrome by Dr. John Newcomer, a leading researcher based at Washington University, and a wellness center where convention attendees can receive advice on such important issues as dental care, nutrition, medication management, and exercise.
- July is Minority Mental Health Awareness Month, and a key focus of the convention will be the vital role that cultural competency plays in the successful diagnosis,

treatment, and recovery from mental illness.

- Dr. Marsha Linehan, developer of the revolutionary treatment approach known as Dialectical Behavior Therapy, will be delivering our Research Plenary.
- At last fall's gala, NAMI featured vocalist Joyce Cooling. Ms. Cooling, a San Franciscan and an active NAMI member, will present a very special evening performance on the convention's opening night.

NAMI's 2009 Convention will continue to offer — as it has for 30 years — up-to-date information on issues of critical importance to people whose lives are affected by mental illness in a wide mix of plenary sessions, symposia, workshops, Ask-the-Doctor sessions, and more, along with s — the opportunity for you to network with hundreds of people whose dedication to improving the lives of people affected by mental illness matches your own.

To learn more, register, and make your hotel reservations, visit our Web site: www.nami.org/convention.



Join House in celebrating NAMI.

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