

the challenger

A Publication of the NATIONAL ALLIANCE for the MENTALLY ILL in Buffalo & Erie County

vol. 21, no. 2
March-April 2005

Mark Your Calendar

March

NAMI Support Group, Wednesday, March 23rd, 7:30 PM, St. Paul's Lutheran Church, 4007 Main Street, Amherst.

April

Southtowns NAMI Family-to-Family Course, Tuesday, April 5th, 6:30 - 9:00 PM, Trinity Lutheran Church, 146 Reserve Rd., West Seneca. Call Debbie or Max at 677-4517 for information and registration.

NAMI Business Meeting, Thursday, April 7th, 7:30 PM, NAMI's Hope House, 432 Amherst Street, Buffalo. If you're a NAMI member, you're welcome to attend.

NAMI Family Meeting, Thursday, April 14th, St. Paul's Lutheran Church, 4007 Main Street, Amherst. Library and hospitality hour: 7:00 PM General meeting: 7:30 PM Guest speaker: Steven Dubovsky, MD, Chair, UB Dept. of Psychiatry

NAMI Support Group, Wednesday, April 27th, 7:30 PM, St. Paul's Lutheran Church, 4007 Main Street, Amherst. (Park in back of church, come in back door (not the side door), first room on your left. There'll be signs.

May

NAMI Business Meeting, Thursday, May 5th, 7:30 PM, NAMI's Hope House, 432 Amherst Street, Buffalo. Watch your Board in action!

NAMI Family Meeting, Thursday, May 12th, St. Paul's Lutheran Church, 4007 Main Street, Amherst. Library and hospitality hour: 7:00 PM General meeting: 7:30 PM Guest speaker: Dr. Robert Weismann, Executive Director, Strong TRies, Rochester.

NAMI Support Group, Wednesday, May 25th, 7:30 PM, St. Paul's Lutheran Church, 4007 Main Street, Amherst.

June

NAMI Business Meeting, Thursday, June 2nd, 7:30 PM, NAMI's Hope House, 432 Amherst Street, Buffalo. All NAMI members are invited.

NAMI Family Meeting, Thursday, June 9th, St. Paul's Lutheran Church, 4007 Main Street, Amherst. Library and hospitality hour: 7:00 PM General meeting: 7:30 PM Guest speaker: Hon. Robert Russell, City Court judge, Buffalo Mental Health Court.

NAMI Support Group, Wednesday, June 22nd, 7:30 PM, St. Paul's Lutheran Church, 4007 Main Street, Amherst.

July

NAMI Business Meeting, Thursday, July 7th, 7:30 PM, NAMI's Hope House, 432 Amherst Street, Buffalo. Come join us!

NAMI Family Meeting, Thursday, July 14th, St. Paul's Lutheran Church, 4007 Main Street, Amherst. Library and hospitality hour: 7:00 PM General meeting: 7:30 PM Guest speaker: to be announced

NAMI Support Group, Wednesday, July 27th, 7:30 PM, St. Paul's Lutheran Church, 4007 Main Street, Amherst.

NAMI Buffalo Initiates Parent-to-Parent Support Project



Many NAMI families find that our educational meetings, our support group, and our Family-to-Family classes are a lifeline of information, understanding, and fellowship with others who know exactly what they're going through.

But for other families who live in the far reaches of our large county, getting to such program is very tricky or just not possible. Weather makes for uncertain driving. Parents can't leave the ill child or lack a babysitter for younger children. Some of our folks no longer feel comfortable driving at night.

Such families may still really need support and someone to talk to or to talk through a problem or just a friendly voice of someone who's "been there."

So we're developing a phone network of experienced, sympathetic parents and siblings who have a couple of hours a month to talk with one or two other NAMI parents every week or two in order to provide emotional support, sympathy, and encouragement for families who can't get to meetings.

We're looking for volunteers willing to become part of our Parent-to-Parent network. Volunteers will undergo a two hour training. For further information call Lynne at 839-0548.

Mailing Address • 264 Hamilton Drive • Buffalo, NY 14226 • 716 839-0548
HOPE HOUSE • 432 Amherst Street • Buffalo, NY 14207 • 716 877- 9415
www.namibuffalony.org

Antidepressants Can Worsen Bipolar Disorder in Kids, Say Advocates



Doctors often diagnose depression and prescribe antidepressants when those medications may not help and may even worsen mania, a syndrome that occurs in children with bipolar disorder. Hellander cited an internal survey of CABF members done in January, 2004, in which hundreds of CABF members reported that their children had first talked of wanting to kill themselves, or harmed themselves, within days or weeks of starting an antidepressant, and were later found to have bipolar disorder. The survey also showed that hundreds of other parents attributed their child's improvement to antidepressants, usually in combination with lithium, or another medication such as an anticonvulsant or an atypical antipsychotic, the standard treatments used to treat bipolar illness in adults.

"Depressed children should be screened for symptoms of mania and carefully evaluated for emerging bipolar disorder (formerly called manic-depressive illness) before taking antidepressants," says Martha Hellander, research policy director at the Child & Adolescent Bipolar Foundation (CABF). Speaking at the annual conference of the American Academy of Child and Adolescent Psychiatry, Hellander hailed the recently announced FDA warnings that antidepressants are associated with an increase in suicidal behavior as a wake-up call to doctors and parents who may assume that all depressed kids have the same illness and need the same treatments.

"Mood disorders in kids are a major public health crisis, and antidepressants are an essential part of treatment for some, but not all, of those kids," she said. "We desperately need more treatments for suffering children who can't take antidepressants and for whom psychotherapy is not enough."

She added that children with emerging bipolar disorder or schizophrenia, both complex genetic illnesses that can emerge gradually during childhood and adolescence, often display symptoms of depression or attentional problems that are not recognized until much later as the early manifestations of these serious, lifelong illnesses.

"Our kids are suffering, and too many are dying or becoming disabled from mood disorders, which are associated with a shockingly high mortality rate exceeding that of some forms of cancer. Bipolar disorder and depression in children are malignant, chronic, and life-threatening brain disorders, putting children at risk of school failure, addiction, and suicide. The FDA's action serves to alert parents and clinicians that a screening for mania—and consideration of different treatments is required."

The language to be added to the warnings on antidepressants includes the recommendation that doctors screen children for bipolar disorder and mania and take a family history before prescribing the drugs. Close monitoring is also recommended, but Hellander raised concerns whether most families realistically can provide a secure, suicide-proof environment with constant supervision. CABF calls for a federal research initiative on pediatric bipolar disorder and depression, similar to those undertaken for ADHD and autism, and suggests that Congress consider mandating insurance companies to cover a two-week inpatient stay for children on antidepressants if recommended by the child's physician, to ensure adequate monitoring.

*Washington D.C.
October 22, 2004*

Handbook for Families Tackles Cognitive Problems in Mental Illness

A new handbook has been developed to help families help their loved ones with the cognitive problems that are part of their mental illnesses.

Serious mental illnesses often significantly affect an individual's ability to think clearly, to pay attention and to remember. Recent research suggests these impairments

may actually be defining characteristics of the illnesses themselves, as opposed to secondary deficits. Accordingly, new behavioral and learning techniques are being developed to alleviate cognitive problems and promote recovery.

"Cognitive Dysfunction Associated with Psychiatric Disabilities: A Handbook for Families and Friends" provides guidelines, advice and information on resources for families to help their relatives with cognitive problems. It was written by Alic6 Medialia, Ph.D., of Montefiore Medical Center and Nadine Revheim, Ph.D., of the Nathan Kline Institute with the support of the state Office of Mental Health.

Single copies of the handbook can be obtained free of charge by writing Dr. Revheim at the Nathan Kline Institute, 140 Old Orangeburg Road, Orangeburg, NY 10962, or by sending her an e-mail at revheim@nki.rfmh.org.

Letters...

Thank you for the endless efforts you and the NAMI Board members make to help all the families and friends in need. You have really made a difference in the well-being of my family and we are all truly grateful.

God bless you and NAMI's future success.

Lucy and Tom Miller

Trivializing Mental Illness

If someone you knew had cancer or diabetes you would never joke about it—would you? Of course not. However, our society continues to joke about people with mental illness. If you or a member of your family had a serious illness, would you be outraged if your insurance company severely limited your access to treatment? You bet you would! However, that's exactly what is still being done to people with mental illness in states which have not enacted parity legislation—the legislation that puts mental illnesses on a par with other illnesses for insurance coverage.

Joking about mental illness (one of the symptoms of a phenomenon known as stigma) and inequalities in parity legislation are only two examples of how we trivialize mental illness in America.

When something is not important we say "it's a trivial matter." That must explain why (with blatant disregard, for the feelings of people with mental illness) manufacturers of products from candy to tee shirts to video games depict (for example) a scary looking person in a straightjacket with the words schizophrenic inside or I forgot to take my medications -- and why movie and television producers create senseless, illconceived scripts that poke fun at mental illnesses for cheap laughs. These purveyors of stigma think it's a trivial matter and that people with mental illness won't mind.

But it is not trivial, it's important. We do mind, and we are doing something about it. In fact, we mind so much that StigmaBusters, a campaign of NAMI (The National Alliance for the Mentally 111) identifies stigma in highprofile situations on national media, in print, and on film, and takes action against the perpetrators. Case in point: *StigmaBusters Alert*, March 2004: "*Cracking Up: One of the Worst*, On Tuesday, March 9, the Fox TV network premiered a new situation comedy: "*Cracking Up*," in which a wealthy dysfunctional family invites a psychology graduate student to live in their Beverly Hills mansion to treat their young son as part of his work toward his degree.

What the therapist-in-training discovers is that the son is fine; it's the rest of the family that gets to him. The mother has bipolar disorder exacerbated by alcoholism. The father is a



Ira H. Minot, CSW

business executive and latent sociopath. The oldest son exhibits obsessive-compulsive symptoms. Their Latino maid is an offensively stereotyped immigrant who wants to flee the "crazy" household, but can't because the family has hidden her immigration papers. The blonde cheerleader daughter? Well never mind. You can imagine.

It's a lot like "The Addams Family" or "The Munsters" from the 1960s, except that the stereotypes and butts of jokes involve mental illnesses and substance abuse. The premiere episode ranks as one of the worst examples of stigma in television history."

A letter writing and phone campaign by *StigmaBusters* expressing outrage over the shows' premise and stereotypes ensued. And the result? *StigmaBusters Alert*, April 13, 2004: *The Fox TV series "Cracking Up" goes off the air after episode six on May 5. Five remaining episodes may be aired this summer, but renewal is deemed unlikely.*

Hopefully one day we will not need *StigmaBusters* — but for now we certainly do. Continually catching and educating perpetrators is an unfortunately tedious process, and very often the damage is done and felt by people with mental illness. Perhaps the federal government will one day enact stiff fines on those who disregard current and ethical standards for discriminating against and wrongfully

ly depicting people with mental illness. *We must stop trivializing mental illness in America.*

For more information about StigmaBusters, go to NAMI's website at www.nami.org and go to "Fight Stigma" under the Take Action toolbar.

The inequalities and discrimination caused by the parity issue is also helping to trivialize mental illness. Many states across America (including Mental Health News' home state of New York) continue to block efforts to enact parity legislation that would elevate mental illnesses to the same level of insurance coverage as other medical illnesses.

In his April 16th editorial entitled "*Put mental, physical ills on par for insurance coverage*" in the *Rochester Democrat and Chronicle*, Dr. John McIntyre, Chairman of the Department of Psychiatry and Behavioral Health at Unity Health System, and past president of the American Psychiatric Association writes:

"On March 16, 2001, Timothy O'Clair, a 12 year old in Schenectady, hung himself. His parents point out that a major factor in their son's death was the inadequate insurance coverage for treatment of his mental illness.

Inadequate coverage is unfortunately the norm: It is estimated that well over 90 percent of private health insurance plans discriminate against persons with mental illness and substance abuse disorders by requiring higher co payments, allowing fewer outpatient visits and days in the hospital, and setting higher deductibles than for other illnesses. This discrimination results from misconceptions and outmoded, unscientific thinking and is part of the stigma faced by people with mental illness and their families.

Mental illness and substance-use disorders are real and disabling illnesses. A large study of diabetes, hypertension, heart disease, lung diseases, arthritis and depression found that only severe heart disease was associated with more disability and impaired daily functioning than depression.

The cost to our economy for untreated and undertreated mental illness and substance-use

disorders is staggering. The National Institute of Mental Health estimates that the annual cost of untreated mental illness exceeds \$300 billion, largely due to lost productivity and other societal costs. A 1999 surgeon general's report estimated that the direct business costs of the lack of parity for mental health coverage was at least \$70 billion per year in the form of lost productivity and increased use of sick leave.

These illnesses can be reliably diagnosed and treatment works. Great advances have been made in the development of criteria-based diagnoses of mental illnesses. Much evidence has emerged supporting specific treatments, and clear practice guidelines have been developed. Several years ago, a landmark NIMH study found that efficacy rates for the treatment of severe mental disorders ranged from 60 percent to 80 percent, exceeding the efficacy rates for many other treatments in medicine. Nondiscriminatory (parity) coverage of mental illness and substance-use disorders is not only affordable, it would save money. In a 1993 report to Congress, the National Mental Health Advisory Council estimated that parity coverage for mental illness would result in more treatment and a net savings of \$2.2 billion per year, largely in costs incurred in the general health care system and society at large.

A few years ago, *The Wall Street Journal* reported that a 'four-year study of program effectiveness (good access to mental health services) at McDonnell Douglas yielded a four-to-one return on investment after considering medical claims, absenteeism and turnover. "

States that have enacted nondiscriminatory coverage have found the resulting increase in health insurance premiums to be relatively small. An actuarial analysis by Pricewaterhouse Coopers, L.L.P. of "Timothy's Law," now being considered by the New York State Legislature, concluded that the expected employer health care costs for this nondiscriminatory health care coverage would rise about 0.8 percent or \$1.26 per member, per month.

Most importantly, nondiscriminatory health coverage is not only the smart thing to do; it is the right thing to do. No matter the form, discrimination is wrong. It makes no sense that the insurance coverage of the treatment of the brain disorders identified as 'mental illnesses

should be significantly less than the coverage of other illnesses.

Thirty-five states have now enacted parity laws with varying approaches to prohibit discrimination in insurance coverage of mental illness. Unfortunately, New York state is not one of them. On the national scene, two years ago, President Bush added his support for nondiscriminatory health care coverage, and there is strong bipartisan support for a national parity bill that Congress is now considering. On March 16, the New York State Assembly passed Timothy's Law by 13110. The fight for parity in New York is now in the Senate. More senators have co-sponsored the bill than are needed for passage, but the Senate leadership has kept the bill off the floor.

The Senate should pass Timothy's Law and end this discrimination against persons with mental illness and their families. The time is now. "

How many more years will we trivialize mental illness and (in this case) have to continue the fight for critical initiatives like parity in insurance coverage? Why are some politicians and insurance company lobbyists able to have the power to block essential legislation, which certainly will result in thousands of people with mental illness being put in harms way?

Trivializing mental illness is the persistent discrimination of people with a treatable illness that sends the wrong message across our nation. It puts people with mental illness in physical danger and sends the message that our society doesn't really care the way it should. Parents and loved ones of people with mental illness also feel the effects and become discouraged when they should be supported in their difficult struggle.

Basic rights to housing, employment, and treatment services should and must be made available at the highest therapeutic levels possible.

The mental health community should not be left out in the cold each year with less funds to provide more services to an ever growing amount of people in need. We must decry budget cuts to mental health services for what they are: the trivializing of mental illness.

Ira H. Minot, CSW
Publisher and Founder
Mental Health News
Summer 2004

5 Things You Can Do to Leave a Legacy

Leave a will. Only 40% of those who pass away have one.

Consider using appreciated assets such as stocks and other securities to fund current charitable gifts and planned gifts during your lifetime. (You'll avoid taxes on the donated assets and the organization will benefit from an increased gift.)

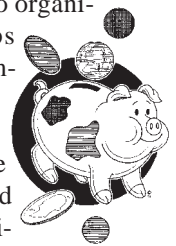
Name NAMI Buffalo & Erie County as a beneficiary of your pension plan, IRA, or retirement plan.

Name NAMI Buffalo & Erie County as the owner and/or beneficiary of a new or existing life insurance policy.

Remember loved ones with memorial gifts. It's particularly important to have a valid will if you have a disabled child who is receiving SSI benefits and/or Medicaid. Inheritance of even a few thousand dollars can make the disabled individual ineligible for benefits!

Tops Markets Community Support Program Changes

Beginning in 2005, Tops Markets has changed its support program for community organizations. Tops will no longer provide a charitable rebate based on grocery tapes collected by such organizations. Tops will, however, offer a 5% rebate to organizations who sell Tops Shopper cards to members and friends.



The gift cards can be used just like cash and are available in denominations of \$10 to \$100 from President Mary Kirkland. Just call her at 832-4035 to order your shopper cards. The Shopper cards can be a significant source of revenue for NAMI Buffalo & Erie County if all our members who shop at Tops use the Shopper cards!

Additions to the NAMI Buffalo and Erie County Library

VIDEO--"Invisible Workforce"— Features a diverse group of consumers, employers, and job developers who talk about the challenges faced by consumers returning to work. It offers sensitive suggestions to help others achieve success joining or rejoining the workforce--19 minutes length.

Multifamily Groups in the Treatment of Severe Psychiatric Disorders, by William R. McFarlane, is a book written by Professor of Psychiatry at the University of Vermont and Director of Research and former Chairman, Department of Psychiatry, Maine Medical Center. The book discusses the importance of social support for people with schizophrenia and their loved ones. It stresses the need for application of a process implementing educational and problem-solving interventions, and managing the clinical, relationship, and functional issues that may arise in treatment.

Integration of pharmacological treatment with family psychoeducation, community reentry and adaptation, and long-term rehabilitation are described. Also explained is the application of this model to a variety of other disorders including bipolar, depression, obsessive-compulsive disorder, borderline personality disorder, and medical illnesses.

This book is especially of interest to families because this process of family education is being promoted by New York State Office of Mental Health to providers to use in educating families and consumers about mental illness.

Grieving Mental Illness, a Guide for Patients and Their Caregivers, by Virginia Lafond, is a self-help book offering guidelines and exercises to help those who have endured the devastating effects of mental illness. Lafond is a social worker in the Schizophrenia Program of the Royal Ottawa Hospital in Canada. The purpose of the book is to help those affected to come to terms with mental illness in positive ways that enhance recovery and rehabilitation.

Bodies Under Siege, Self-Mutilation and Body Modification in Culture and

Psychiatry, by Armando R. Favazza, MD, explores a topic not easy to examine, but to families dealing with piercing and cutting behaviors in a loved one, it offers some in-depth information about causes and cultural perspectives for this disturbing practice.

Historical details and cultural rituals may not be the primary topics interested readers are looking for, but the chapters on understanding self-mutilation, and biological and psychological findings, and treatment issues are most interesting to anyone needing information on these behaviors. A word of caution: this is not an easy book to read!

Marcy Rose



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The Challenger

Editor: Lynne Shuster

Letters...

I've worked with troubled adolescents for the last 14 years at Renaissance House and have been in the human services field for over 20 years. I've always been dedicated to helping troubled teens. But now, I can't seem to get my 15 year old son, who has co-occurring disorders the services he needs. (Talk about frustrating!)

Like many parents of dually diagnosed children, I've made an extensive search to find a treatment facility for my son. He's been denied admission to numerous treatment facilities throughout New York State because he did not meet rigid admission criteria.

Recently, my son, while he was in crisis and required hospitalization, has been turned away countless times from Erie County Medical Center - CPEP because of the lack of beds in Erie and surrounding counties. I was left to take my son home. Sixteen days after he was denied admission, he swallowed 37 Tylenol P.M.'s.

When he was taken to the hospital, he said, "You left me no other choice. I was crying out for help and you left me to die." My son is right! The lack of services in this area will be the death of my son.

My Michael is currently at BryLin. This is an acute, short-term psychiatric unit. My son is in need of long-term psychiatric stabilization. I'm sure you're thinking, WNY Children's Psychiatric Center, in West Seneca...There's up to a six month waiting list. Or, maybe you're thinking, "The Intensive Home-based Services program. There again, another waiting list!

Yet 80% of the children in these facilities in Erie County and Niagara County are residents from outside this geographic area. I don't want to deny any child the services he needs, but don't we have an obligation to serve our own first? WNY Children's Psychiatric Center has 34 beds for adolescents. How can they possibly provide care for children from 19 counties? And three of these very scarce beds are allotted to court mandated children from outside Erie County. If Erie County is supposed to be responsible for kids in 19 counties, shouldn't more beds be available?

And shouldn't children from Erie County receive preferential treatment?

West Seneca Developmental Center sits vacant. It is located on the same plot of land as Children's Psych Center, but is not fully utilized. Why can't we look at the vacant buildings and utilize a facility for psychiatrically disabled teens that already exists?

My Michael hates me...because I couldn't help him nor get him the help he needs...because I didn't let him die. And to think that WNY Children's Psychiatric Center is in walking distance from my house, but he waits for a bed while children from other counties get the services they need.

Kathy Dasta



In Brief...

The Erie County Department of Mental Health has a new commissioner, Phillip Endress. Mr. Endress has been Commissioner of Mental Health in Oneida County for the last eighteen years. He began his human service career as a counselor at Community Concern of Brant and Evans when that now-independent agency was a site of Lake Shore Behavioral Health Services. Mr. Endress has a masters degree in Social Work and a second masters degree in Business Administration. We wish him well in his new very challenging position.

NAMI Buffalo & Erie County has received confirmation of a \$16,000 grant from the Erie County Department of Mental health which will partially defray the expenses of publishing the latest, sixth edition of *The Mind Matters*, with a pre4ss run of 10,000 copies. Our warmest thanks to Peter Curtis, Deputy Commissioner of the Erie County Dept. of Mental health for facilitating the grant which will make publication of the new edition possible.

Lynne Shuster, NAMI Coordinator, has been named a 2005 "Health Care Hero" by Business First" as a "Health Care Volunteer for donated time and unlimited compassion for an organization in the health care field." Lynne was nominated for the prestigious award by Tom McNulty, President of Success Stories, and also president of NAMI's Citizens Volunteer Board.



Please Remember

*NAMI
Buffalo*

&

*Erie County
in your Will*



ROAD BLOCK?

Tips for advocates on busting through.

The Treatment Advocacy Center's mission is to eliminate barriers to treatment. While our main focus is changing laws and policies to encourage early intervention and sustained treatment, we get enough calls and e-mails to know that many of our friends are fighting individual battles every day to secure treatment for someone they care about. Following are some strategies to help overcome common roadblocks to personal advocacy.

OBSTACLE: Unresponsive System.

SOLUTION? Draw attention to your situation.

It is extremely frustrating when you are trying to help someone, but the system is unresponsive. Here are some suggestions for getting action from a slow-moving or unresponsive bureaucracy.

Be an advocate first, a friend second. Building relationships with a service provider and letting them see how much you care about your loved one is vital and demonstrates your value as a member of the treatment team. But don't get too cozy. It is more important to be an advocate than to be friends with service providers and mental health officials. Sometimes, cooperation is not possible. Feel free to disagree. It sometimes may even be necessary to go over someone's head.

Navigate up the chain of command until you find a decisionmaker who will help. Jails, hospitals, treatment facilities - each has an established chain of command. Work your way up the chain until you get results. For example, the chain of command in an inpatient setting may start with a social worker. From there, contact a nurse, psychologist, or psychiatrist. Next, ask for a treatment team leader or section chief. If those attempts fail, contact the hospital administrator. Document each

attempted contact or conversation by e-mail or fax.

Finally, most organizations have oversight from a Board of Directors or Trustees. The identity of board members is a matter of public record. Write them a short letter documenting the problems and lack of responsiveness. The board has a fiduciary responsibility to ensure that the organization's mission is met and will likely investigate and address your complaints. For publicly funded services, you can work your way up from the director of mental health services to the Governor. We have seen well-documented cases get a Governor's attention — and results.

Send a telegram. Once a very common method of delivering urgent messages, telegrams are not used as often anymore because there are faster means of delivering messages. But, being less common, they definitely get people's attention.

Hire an expert. If you can afford it, an expert can be a huge help. Different situations call for different experts. For instance, health care providers are often more responsive when an attorney makes contact. Getting help in a jail or correctional facility can be easier with the assistance of a correctional expert.

Involve law enforcement in your personal advocacy. If the person you are trying to help has repeated contacts with law enforcement, you may be able to get a sheriff or police chief to intervene. Help them understand that getting treatment for your loved one is in everyone's best interest - it could help avert a tragedy. A call from a sheriff or police chief can be very influential in prioritizing services for someone you care about.

Get the media interested. Television and newspaper reporters cannot cover every story they hear about. But if your situation is particularly egregious, heart wrenching, or representative of a systemic problem, your local media outlet might be interested. Find contact information on their website and focus on a reporter who is in your com-

munity, especially if they have covered mental illness or crime issues before. When you call, summarize your story in one sentence and keep your comments focused on one main issue (treatment, insight, criminalization, etc.). Picture the headline that you want to see and make that your theme. ("Man jailed for tenth time in five years because the law can't help him: Mother demands answers.")

OBSTACLE: No services for your loved one.

SOLUTION? Look in new places.

Those who are the most severely ill often cannot get the services that they need. If you are unsuccessful in finding needed services for someone you care about, you may want to try some of the following strategies.

Know what services are available in your community. Your local NAMI affiliate is a good place to start researching what is available. But do not assume that they are aware of all existing services, because specialized services are often a well-kept secret. You may have to dig deeper: does the community have intensive case managers, intensive family support services, residential support services, etc.? The only way to find out is to ask. Contact your state or local mental health administrator. Research what is funded by the state budget in your local area. Visit the mental health center or local mental health service providers and request a tour. Don't accept the first answer you get.

Know the eligibility criteria. Some specialized services (such as PACT teams) are reserved for specific populations. Does your loved one meet the criteria? Don't assume that the answer is "no." Ask for written policies governing eligibility. Use the eligibility criteria and the person's

treatment history (for example, repeat hospitalizations) to document that the person is eligible for those services.

Document the costs of not providing services. There is often a financial disincentive for providers to serve the most severely ill - they may require intensive treatment, and that costs money. One way to counteract this is to document what it costs not to provide those services. For a person who is repeatedly hospitalized, the cost can be determined for a specific period by multiplying the cost per day by the total number of days. A state or county mental health administrator will appreciate the argument that providing the needed community services will be less expensive in the long run.

Obstacle: Confidentiality

SOLUTION? Understand the law

Sometimes concerns about breaching confidentiality are raised by treatment providers as a reason not to talk to a third party, even one trying to help a loved one who is receiving or in need of treatment. Sometimes confidentiality is used inappropriately. Here are some important things to remember:

Share what you know with the provider. Even if treatment providers cannot tell you about someone's condition or treatment, they can listen. In fact, some would argue that it is negligent for a mental health professional not to gain as much information about the person's condition as possible.

Don't assume the provider has done everything they can. If a provider tells you that they don't have permission to talk with you, don't automatically assume that they sought permission. Ask whether they sought permission from the person you are trying to help. Make sure they at least ask the question.

Don't be intimidated when someone says HIPAA. HIPAA is often used as a shield to sharing information about a person's condition or treatment. HIPAA is the "Health Insurance Portability and Accountability Act of 1996" and is designed to create a

national standard for certain types of health care information. It does not absolutely preclude families from obtaining information about a loved one's treatment.

- A patient has a right to request copies of their medical records. Gather these records when someone is not in crisis. Keeping copies of past treatment records can be invaluable if a future crisis occurs.

Individuals who have power of attorney or guardianship are considered a personal representative and are entitled to full access to the patient's medical records.

- HIPAA provides for a formal authorization process in which a patient can give written permission to disclose treatment information. The authorization must be specific in terms of what information can be disclosed, to whom, and for how long. The individual can revoke it at any time. But, if the patient is willing to give authorization, this prevents a health care provider from not disclosing information.

- A less formal process is available. The provider can discuss treatment when the patient is present with the inquiring family member and the patient has an opportunity to "agree or object" to the disclosure.

- There is also a "best interest" rule that applies when a patient is incapacitated, in an emergency situation, or not available. In those cases, a provider may disclose information determined to be in the "best interest" of the individual.

Jails and correctional facilities are exempt from some HIPAA provisions and can obtain medical information about an inmate for many purposes, including the provision of health care to such individual. This is important if a loved one is in jail and the jail is trying to get information from a prior health care provider.

- At least twenty-one states also have their own laws governing confidentiality. Some state laws may impact the "agree or object" or the "best interest rule." For state-specific information, consult web sites like these: www.cdc.gov/privacyrule/privacy-links.htm OR www.healhfprivacy.org/info-url_nocat2304/info4url_nocat_search.htm Compliments of The Treatment Advocacy Center. Visit us online at www.psych-laws.org or call us at 703 294 6001.



Thanks...

To **Barbara Utter** for eloquently presenting our cause to First Presbyterian Church of Clarence which has made a \$250 donation to NAMI Buffalo

To **Mike and Marsha Devine** for arranging a donation to NAMI Buffalo from the orchard Park American Legion.

We're grateful to all our members who seek out source of help for us, as the way is long and the road is steep.

Spotlight on Health

Saturdays 8:00-8:30 a. m.

Hosted by

Tom McNulty

On

WECK-AM 1230

A Production of

Success Stories, Inc.

Sponsored by:

**Catholic Health System/
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Thanks...

To Marcy Rose and **Gerrie Cruz** who have just begun our most recent Family-to-Family class.

To **Mickey Delaney** for her assistance with the last big batch of Tops tapes to get them turned in by the deadline.

To our wonderful "Christmas is for Kids" volunteers: **Tom McNulty**, President of Success Stories and Co-Chair of this huge holiday project;

NAMI President **Mary Kirkland** and husband **Jim**, for many, many hours of pre- and post-organization, pickups and deliveries, to our "always there" volunteers, **Pat and Roger Watkins**, for so many hours of good works, **Sue Keppel**, for pre-event organizing; and to **Mary Pilon, Marcia Bucella, Stacey Bevilaqua, Herman Szymanski, Kathleen Kirkland, Bill Birmingham, Carolyn Vujnovic, Miriam Becker, Colin McNulty, Kari Lambricht, Nancy Smith, Lucy Miller, Wanda Haak, Doris Sielski, Joan Snyder, Tom Wahler, Sue Minotti, Tim Eagen and Jo-an Campbell** for many hours of wrapping, sorting, packing, and delivery to "our" kids at Amith House, Compass House, Haven House, Cornerstone Manor, WNY Children's Psych Center Outpatient and Day Treatment Programs, ECMC's adolescent unit, and BryLin's child and adolescent unit.

To **Barbara Utter** for arranging an outpouring of gifts from Clarence Presbyterian Church and the **quilters of Townline Lutheran Church** for more than fifty quilts to keep a child warm on a cold winter night.

To **Jennifer Bevilaqua** for arranging for a Tops gift certificate to provide refreshments for all our volunteers.

To **Nancy McNulty** who had a lovely party and put the arm on all her guests to bring gift certificates for the kids.

To the wonderful folks at **Cannon Design, Good Shepherd Episcopal Church, The Mansion of Delaware, Main Urology Associates, the 8th grade class of Nativity of Our Lord School** and to

Bridget McNulty for involving her fellow students, **Blue Cross Blue Shield of WNY employees, the staff of Independent Health, Genesee-Transit Pediatrics, Horizon Human Services, Quaker Medical Associates, TLC - Staff Builders, Excelsior Orthopaedics**, for wonderful gifts and financial support, **Bob Hill** of Infinity Broadcasting for publicizing our project on radio, and to **all our contributors** who this year's "Christmas is for Kids" an outstanding success.



Additions to the NAMI Buffalo & Erie County Library Video

Invisible Workforce Features a diverse group of consumers, employers, and job developers who talk about the challenges faced by consumers returning to work. It offers sensitive suggestions to help others achieve success joining or rejoining the workforce--19 minutes length.

Multifamily Groups in the Treatment of Severe Psychiatric Disorders, by William R. McFarlane, is a book written by Professor of Psychiatry at the University of Vermont and Director of Research and former Chairman, Department of Psychiatry,

Maine Medical Center. The book discusses the importance of social support for people with schizophrenia and their loved ones. It stresses the need for application of a process implementing educational and problem-solving interventions, and managing the clinical, relationship, and functional issues that may arise in treatment.

Integration of pharmacological treatment with family psychoeducation, community reentry and adaptation, and long-term rehabilitation are described. Also explained is the application of this model to a variety of other disorders including bipolar, depression, obsessive-compulsive disorder, borderline personality disorder, and medical illnesses.

This book is especially of interest to families because this process of family education is being promoted by New York State Office of Mental Health to providers to use in educating families and consumers about mental illness.

Grieving Mental Illness, a Guide for Patients and Their Caregivers, by Virginia Lafond, is a self-help book offering guidelines and exercises to help those who have endured the devastating effects of mental illness. Lafond is a social worker in the Schizophrenia Program of the Royal Ottawa Hospital in Canada. The purpose of the book is to help those affected to come to terms with mental illness in positive ways that enhance recovery and rehabilitation.

Bodies Under Siege, Self-Mutilation and Body Modification in Culture and Psychiatry, by Armando R. Favazza;M.D., explores a topic not easy to examine, but to families dealing with piercing and cutting behaviors in a loved one, it offers some in-depth information about causes and cultural perspectives for this disturbing practice.

Historical details and cultural rituals may not be the primary topics interested readers are looking for, but the chapters on understanding self-mutilation, and biological and psychological findings, and treatment issues are most interesting to anyone needing information on these behaviors. A word of caution: this is not an easy book to read!

Tops Tapes Final Report

Fun figures from Barbara Rex, our tireless Tops tapes compiler: since March, 1996 when our NAMI folks began turning in the tapes to Barb, she has turned in \$1,736,000 worth of tapes and NAMI received \$3,053.52 for them. As Barb notes, Thanks to all the people who saved tapes and either sent them or turned them in; they all a part of those figures."

[A special, HUGE thanks to Barb for all those hours of counting and compiling over the years. ED]

Support Group for Parents of Ill Children and Teens

A support group for parents, guardians, grandparents or other family members of children and young teens with emotional and behavioral problems sponsored by

**WNY Children's
Psychiatric Center.**

WNYCPC Community Services
Buffalo Outpatient Center
575 Alberta Drive
Suite 200
Amherst, NY 14226

*(The door to the facility is on the
Bailey Ave. side of the building)*

7:00 - 9:00 pm

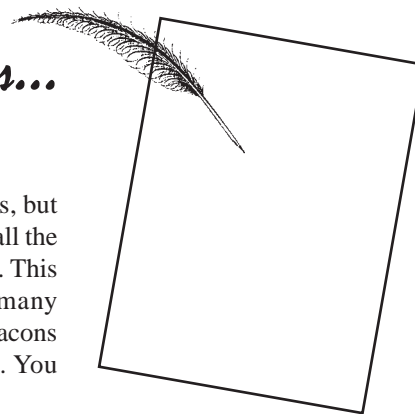
**2nd and 4th Thursday
of each month**

Child care provided free of charge.

For additional information, call:

Carolyn Vujnovic 677-7079
Bill Bermingham 832-0720 ex.
6849

Letters...



Thank you for your holiday greetings, but most of all, for all you do throughout all the seasons. Your efforts are so important. This past year has been another with so many tragedies in the world and we need beacons of hope and action for those in need. You are indeed bright beacons.

Thanks for your help with J. and for so many others who have too often nowhere else to turn. God bless you and all those working for the rights and dignity of those afflicted with mental illness, and for providing support to family members who have too many times been considered part of the problem by mental health workers, rather than the solution.

May this new year bring you good health and continued support of others to serve our Creator by helping lift up those who are struggling with greater foes than any of us blessed with good health can know.

Daryl B. Denning



New NAMI Family-to-Family Course: The Southtowns

***Family to Family is coming
to the Southtowns area!***

**Classes begin: April 5th
Classes end: June 28th**

6:30 - 9:00 PM

Trinity Lutheran Church
146 Reserve Road
West Seneca, NY 14224

**For information call:
Debbie or Max at 677-4517**

Classes cover the major diagnoses including bipolar disorder, schizophrenia, major depression, anxiety disorders as well as medications and side effects, symptoms, problem solving, communicating with someone mentally ill, and effects on the family.

It's a "life-changing" experience

NEW YORK TIMES EDITORIAL

The War on Affordable Housing

Ideologues in the Bush administration would like to dismantle Section 8, the most successful public-and-private housing partnership in the history of the United States. That's the only way to explain the destructive policies emanating from the Housing and Urban Development Department, which has been hammering at Section 8 all year. The conflicting signals and general aura of hostility have convinced housing authorities around the country that they need to defend themselves by avoiding new commitments and cutting back on their old ones.

Even worse, the developers who have counted on Section 8 money to build affordable housing for the poor, the elderly and the disabled now think that they can no longer trust this program. Republican lawmakers whose districts are being hurt have kept quiet in the name of party solidarity. But this posture of loyal complicity will be difficult to maintain as the housing crisis deepens, which it surely will if HUD continues along its current course.

A landmark program, Section 8 has produced affordable housing for needy Americans since the Nixon years. It works this way: instead of doing the construction itself, the government guarantees subsidies for rents in the private market. Families, most of them at or below the poverty level, pay 30 percent of their incomes toward rent, and Section 8 vouchers pay the rest.

At the moment, the program covers about two million people, a majority of them elderly or in families with children. Developers building affordable housing have come to depend on Section 8 guarantees for financial backing.

Things are getting worse by the day, thanks to ideologues in the Bush administration who prefer a laissez-faire approach, regardless of the social costs. Unable to dismem-

ber the Section 8 program directly, HUD has chosen to destabilize it with a series of rule changes and budget maneuvers that are being felt from coast to coast. The current HUD secretary, Alphonso Jackson, has settled on a particularly destructive strategy involving misdirection and sleight of hand. He releases poorly explained policies that include hidden, but draconian, cuts. After



an outcry from Congress, he retreats to lesser cuts that leave the program diminished, housing authorities confused and the general public mistakenly believing that the status quo has been regained.

The latest incident, laid out by The Times's David Chen, came after HUD released a vaguely worded and irrational proposal that involved reducing the value of housing vouchers for poor residents in some of the most expensive housing markets in the country. The proposed change was widely thought to have been rescinded after housing advocates and lawmakers raised a fuss. But a close look at the data shows that HUD still seems to be planning to enforce a part of the plan that would make it more difficult for large families to find larger apartments. The landlords have been quick to react.

Faced with the prospect of Section 8 vouchers that pay less than fair-market rents, they have made it clear that they will simply refuse to deal with the program, especially in tight markets where they can pick and

choose tenants. That will be a disaster for poor families with several children.

The insanity of this ideologically driven attack on Section 8 is underscored in a bipartisan book written by two Republicans and two Democrats just out from the Joint Center for Housing Studies at Harvard. The authors include two former housing secretaries: Jack Kemp, a Republican, and Henry Cisneros, a Democrat. The authors argue convincingly that the country is sacrificing both families and neighborhoods by hacking away at the most successful housing program in history.

The book, "Opportunity and Progress," calls for restoring the sane bipartisan effort that produced the federal housing program in the first place. Most significantly, the authors urge Congress to insulate the housing program from partisan sniping by creating a national trust fund. Modeled on

similar programs that work well at state and local levels, that national fund would be used to build, rehabilitate and preserve 1.5 million affordable apartments.

The proposal resembles one already pending in Congress, where a trust fund bill is bottled up in committee even though it has more than 200 sponsors.

The bill, as originally introduced, would finance itself by redirecting a small portion of the profits from the Federal Housing Administration's mortgage insurance fund. This page is generally suspicious of dedicated funds, but, given the national housing crisis, it makes good sense to direct money earned from housing back into housing. The bill would certainly have wide support, if only the Republican leadership allowed it to be brought to the floor.

New York Times
October 16, 2004

Why TAC Exists: to Save Lives

[TAC is an abbreviation of The Treatment Advocacy Center of Arlington Va. They publish an excellent free Newsletter. Ed]

On February 10, 2003, the Washington Post carried a story about Joseph Hilliard, a 60-year-old man in Washington, D.C., who was charged with brutally murdering another resident of his boardinghouse. Hilliard, diagnosed with paranoid schizophrenia and not on medication. had 30 years earlier murdered another During the intervening years, he had been inadequately treated and not maintained on the medication needed to control his symptoms.

This is not a unique or isolated case. I remember in the late 1980s seeing a very psychotic woman in my clinic at a homeless shelter in Washington. Twelve years earlier, equally psychotic, she had murdered her daughter. In the intervening years, she had been hospitalized, done very well on medication, and eventually been released with no requirement to continue taking her medication.

The public would be astounded if they realized how frequently this occurs. Because of the push by well-meaning but misguided civil libertarians and antipsychiatry groups, keeping individuals with schizophrenia on medication once they leave the hospital has become exceedingly difficult. And this is true even for individuals like Mr. Hilliard, who has proven himself to be dangerous. Many people with schizophrenia, like Mr. Hilliard, will not take medication involuntarily because they do not believe they are sick. They lack awareness of their illness because of brain damage caused by their schizophrenia.

We founded TAC because there was no public voice to reply to the civil libertarians and antipsychiatry groups. TAC exists man. to bring reason and scientific understanding to the medication debate. TAC exists for Mr. Hilliard and other patients like him. TAC exists, ultimately, to save lives.

E. Fuller Torrey, M.D.

Web Site: www.psychlaws.org
E-mail: info@psychlaws.org

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Shari Augustyn, *in honor of my daughter Tracy*

Our members and friends donating through the Combined Federal Campaign
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A Legacy for a Better Tomorrow

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Anonymous	Anne & Herman Szymanski
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Christmas is for Kids

Star Circle \$1,000 - \$1,499

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Christmas Angels \$500 - \$999

Suzanne T. Johnson

Santa's Circle \$100 - \$249

Tom McNulty

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WNY Healthcare Executive Forum

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Mary E. Smythe, LMSW, *in memory of Kay & Walter Williams,
and Helen & John Smythe*

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**We invite you to join
NAMI Buffalo & Erie County
in helping us make a difference for people
with mental illness and their families**

Mail to:

NAMI in Buffalo & Erie County

264 Hamilton Drive

Amherst, NY 14226

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____ E-Mail _____

- Benefactor \$100 - \$250
- Patron \$75 - \$99
- Sustaining Member \$50 - \$74
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- Individual Membership \$25
- Consumer Membership \$12
- Associate Membership for Mental-Illness Professionals \$20

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- Please keep my membership/contribution anonymous.

*If you also want to be a member of NAMI New York State,
add \$3.00 to your membership dues. If you want to be a
member of the National NAMI, add \$10.00 to your dues.*

**No one will be denied membership due to financial
hardship. If you are on a limited, fixed income,
contact Barbara Rex at 633-8512**

I'd like to help with the following:

- Fund Raising Office & Clerical Phone Tree
- Legislative Advocacy Speakers Bureau

Other _____

I'd like to be put on the phone tree to receive
legislative or other alerts. Yes No

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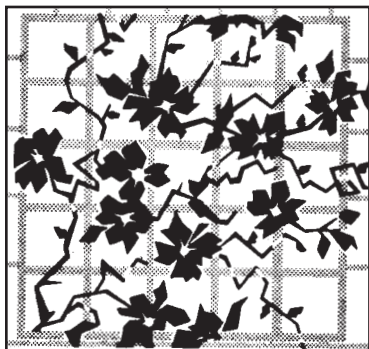
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NAMI

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*Life is a big canvas.
Throw all the paint on it you can.*



Thanks to Eli Lilly & Co. for underwriting this issue of *The Challenger*