

the challenger

A Publication of the NATIONAL ALLIANCE on MENTAL ILLNESS in Buffalo & Erie County

Vol 1 No. 4
August- September 2009

Mark Your Calendar

All regularly scheduled monthly meetings are held at St. Paul's Evangelical Lutheran Church, 4007 Main Street, Amherst (near the intersection of Main and Eggert Rd.), Board meetings and monthly educational meetings are held on the second floor (main entrance at the back of the church). Support group meetings are held on the first floor (church entrance at ground level at left rear of the building).

August

NAMI Board Meeting, Thursday, August 6th, 7:30 PM. Members welcome!

NAMI Educational Meeting, Thursday, August 13th Library and Coffee Hour- 7:00 PM. Presentation: 7:30 PM. Guest speakers: Thomas Dodson, Executive Director, Buffalo Psychiatric Center and Celia Spacone, MD, on new programs at BPC.

NAMI Family Support Meeting, Wednesday, August 26th, 7:00 PM.

September

NAMI Board Meeting, Thursday, September 3rd, 7:30 PM. Attend a Board meeting, and consider volunteering to serve on the Board.

NAMI Educational Meeting, Thursday, September 10th Library and Coffee Hour- 7:00 PM. Presentation: 7:30 PM. Guest speaker: Police Officer Rey, Orchard Park Police on how police handle "emotionally disturbed persons" (EDP's).

NAMI Family2Family, 12-week course on coping with serious mental illness, beginning September 14th at St. Paul's. For information and/or registration call Gerie at 877-2076.

NAMI Family Support Meeting, Wednesday, September 23rd, 7:00 PM

October

NAMI Board Meeting, Thursday, October 1st, 7:30 PM. All members welcome!

NAMI Educational Meeting, Thursday, October 8th Library and Coffee Hour - 7:00 PM. Presentation: 7:30 PM. Guest speaker: Nancy Singh, Restoration Society, on new programs and program changes.

NAMI Family Support Meeting, Wednesday, October 28th, 7:00 PM.



The Tragedy of Mental Health "Care"

All families know the heartbreak which arrives at their doorstep when serious mental illness strikes a dearly loved son or daughter, a parent, a husband or wife. There are the broken dreams, the lost hopes for the future, the sadness, confusion, lack of knowledge and understanding at the beginning of the long, hard journey. There's the grief when we realize it's a not a temporary thing like the flu or a "phase" that adolescents go through. There's the pain of profoundly changed lives, and shrunken expectations, the worry, anxiety, and exhaustion of trying to make peace with what has come to pass.

One of the last hopes lost is that there will be a network intelligently designed, compassionately and thoughtfully put in place, to treat, guide, and care for our very disabled loved ones who can no longer reach for the future in the ways we had anticipated.

Again and again, we find bureaucrats, administrators, psychiatrists, social workers, receptionists, case managers who blame the families and the patients when the system has failed to meet a patient's needs. We encounter lazy staff, rude receptionists, lost communications, lab tests not done or results not read, appointments cancelled without notice, constant staff turnover, inexperienced and under-trained staff "practicing" on our son or daughter, insurance companies paying agencies as little as \$11 for a patient visit, nonexistent or garbage discharge "plans", patients shuffled out of the hospital when insurance runs out or length of stay gets "too long" regardless of how sick they are.

Families and patients become the pawns, the expensive "hot potatoes", to be passed from one agency or hospital to another, with little thought or concern for their welfare or the consequences of such actions.

Some people/patients survive such treatment, though often at great cost. But many

Continued on page 2

Mailing Address • 302 Parkhurst Blvd. • Buffalo, NY 14223 • 716. 832.4035

EMAIL: namibuffalo@aol.com

find themselves caught in a terrible web where there is no real help, no realistic or careful attention to what the patient needs or wants. **All the talk of the last few years of a "patient-centered system" is drivel, a fiction devised by bureaucrats, driven by politicians, costs, and political agendas.**

Families have become conditioned to half a loaf of care. Now even the crusts are disappearing in New York State's economic meltdown.

State Staff Cuts

Gov. David Patterson has threatened to cut nearly 9,000 state staff, including 1,100 mental health staff. A recent deal with the state's powerful unions will instead offer "buyouts" for early staff retirements, creating vacancies which will not be filled.

State psychiatric facilities are in a desperate race to reach the cuts mandated by the governor and flowing from Albany's NYS Office of Mental Health. Such staff reductions will be accomplished by devising new fictions about the sickest patients; that they can live in the community no matter how ill they are. That the sickest patients don't need long-term state hospital care (expensive) and can do fine in community residences (cheaper) with less staff, less supervision, less support, more "freedom", or even in a crummy independent apartment (cheapest) in dangerous neighborhoods where a staff member low on the totem pole "drops by" once a week or so and the patient is free to live in filth, preyed on by neighbors, an inadequate diet, social isolation, and fear.

The Impact of Cuts in Buffalo

According to our sources, we will lose nearly 35 long-term beds at Buffalo Psychiatric Center. Two units housing 52 patients in the Strozzi Building are being converted to "community residences" with 14 patients each. (How the bureaucrats get around hospital staffing standards and regulations to accomplish this sleight-of-hand is not yet known to us.) Plans are changing weekly, or even daily. There will be large staff reductions. There is, for all practical purposes, no longer any long-term care at BPC. Inpatients at Erie County Medical Center, or Buffalo General, wait weeks or months for a BPC evaluation team to "assess" them, only to be refused admission in many cases, no matter how sick they are.

BPC drops length of stay. The psychiatric center, with Albany cracking the whip, now uses smoke and mirrors to reduce length of stay to "intermediate term care". One patient, at BPC for 33 years, went to ECMC for inpatient medical treatment. He was discharged from BPC, then readmitted once he left ECMC. There was much celebration among various administrators that this chicanery dropped their aggregate length of stay significantly.

Patients are being discharged to a new BPC Assisted Community Treatment (ACT) team, established because no other community agency is equipped to deal with these profoundly ill individuals, and such agencies have sensibly refused to accept them.

Sadly, for some patients, the best life possible has been, and should continue to be, living in a state psychiatric hospital. They are accepted. No one makes fun of them. They are kindly treated by most staff who know them well. Their living quarters are clean. Their laundry is done. They have lovely grounds to walk. Their meals are balanced and regular. They don't need money to meet basic needs. They have a home, a refuge, a sanctuary. Would we have chosen such a life for them? No indeed, but we have had abundant reasons to be thankful that places like BPC exist to care for those who are so very ill.

There is an absolute refusal by NYS Commissioner of Mental Health Michael Hogan, (driven by the politicians and costs) to recognize that according to almost all knowledgeable authorities, one-third of patients with serious mental illnesses such as schizophrenia, schizoaffective disorder, and bipolar disorder will remain seriously ill for much of their lives. Hogan and other bureaucrats answering to him cling to the fiction that all patients will "recover", though they are careful not to define that concept.

The thousands of mentally ill people in our state prisons and county jails, wandering homeless and living in shelters or scummy rooming houses, are testimony to that falsehood. There is no threshold too awful to cross regarding a patient's misery or incapacity, so long as the numbers are met and "success" is achieved and the statistics look good.

These are dark times, indeed, if you have a loved one with a serious mental illness. ■

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Large Study Points to Common Genetic Determinants Linking Schizophrenia and Bipolar Disorder



A broad-based study of data from more than two million nuclear families in Sweden has provided evidence of possible common genetic determinants of schizophrenia and bipolar disorder.

Reporting their results in the January 17 issue of the journal *The Lancet*, the authors, who include NARSAD Distinguished Investigator Tyrone D. Cannon, Ph.D., of UCLA, explained the goal of their study. "Whether schizophrenia and bipolar disorder are the clinical outcomes of discrete or shared causative processes is much debated in psychiatry. We aimed to assess genetic and environmental contributions to liability for schizophrenia, bipolar disorder, and their comorbidity."

To achieve their goal, the researchers merged data from the Swedish multi-generation population register, which contains information about all children and their parents in Sweden, and the hospital discharge register, which includes all public psychiatric inpatient admissions in Sweden and the Swedish hospital discharge register. These data spanned the period 1973 to 2004.

Risks for schizophrenia, bipolar disorder and their co-morbidity were assessed for biological and adoptive parents, offspring, and full and half-siblings of individuals with one of the diseases. The results, the researchers stated, clearly showed increased risks of both schizophrenia and bipolar disorder for first-degree relatives with either disorder. Evidence from half-siblings and offspring adopted away shows that this is due substantially to genetic factors.

"Similar to molecular genetic studies, we showed evidence that schizophrenia and bipolar disorder partly share a common genetic cause. These results challenge the current nosological dichotomy between schizophrenia and bipolar disorder, and are consistent with a reappraisal of these disorders as distinct diagnostic entities."

An editorial note accompanying the article asserts the significance of the breadth of the study, as opposed to most previous genetic epidemiological studies, which "have been underpowered to investigate the question of diagnostic overlap."

Also collaborating in the study were scientists from the Karolinska Institute and Uppsala University, in Sweden, and the University of North Carolina, Chapel Hill.

NARSAD
Great Neck, N.Y
February 16, 2009

Our Sympathy...

To long-time members **Ann Ezzo**, and **Mickey Delaney**, who both lost their husbands recently.

Thanks...

To long-time NAMI Board Recording Secretary, **JoEllen Pennella**, who is retiring from the Board, but plans to continue her involvement on the Hospital Care Committee, and as one of our excellent Family2Family teachers.

To our superb library staff, **Marcy Rose**, who continues her work searching out the best of print and video materials for our library even while recovering from serious surgery.

To our circulation coordinators, **Rosemary Donnelly** and **Nora Roberto**, who also serve as our educational meeting greeters and attendance registrars.

To **Bill Donnelly**, Rosemary's son, who spent many hours at the computer compiling our library directory.

To **all our members who kindly provide refreshments for our monthly educational meeting.**

To **Gerie Cruz**, our faithful Family Support Group leader.

And, always, to **Sue and Jerry Keppel**, for setting up for our monthly educational meeting, hauling cartons and cartons of brochures and getting them out on our reader's table, arranging our attractive refreshment table, and making sure everything is shipshape when we finish.

To **President Mary Kirkland** for hours and hours on the phone and first husband, **Jim**, who hauls many, many cartons of our guide *The Mind Matters*, to various hospitals, agencies, and organizations, takes dozens of messages for Mary, ferries cartons of toys and gifts for Christmas is for Kids, and keeps the home fires burning when Mary is out in the world on NAMI business.

Clinicians - The Worst Purveyors of STIGMA?

In a previous blog, I mentioned an email interview I recently completed with *I Am Bipolar*. "Have you ever experienced negativity or stigma from people who have become aware of your condition?" Michael, who runs the site, asked.

Hmm. Interesting question.

"Ironically," I replied, the worst stigma came "from clinicians and fellow patients, the very people who are also my best supporters."

Clinicians have long accepted me as a journalist. In 2007, in fact, they even honored me with a major international award. But I am not one of them and never will be. Last year, I was invited to give a grand rounds lecture at a psychiatric facility in Princeton. I accepted with some trepidation. It is not my place as a journalist to tell others how to do their jobs.

I showed up with a talk on medications compliance. I'm sure the 50 or 60 clinicians in the audience expected me to blame patients for being too stupid to work the child-proof cap to their meds bottles and such, and indeed I did touch on that. But I also blasted the pharmaceutical industry for aggressively marketing meds that often made us worse rather than better, as well as clinicians who should know better, at the expense of the individuals they are supposed to be serving.

I wasn't just some antipsychiatrist spouting off. My PowerPoint contained reams of citations from the leading psychiatric authorities, including conferences I had attended and first-rank journal articles and editorials. But it was also my duty to wrap it all up and tie it in a bow. With reference to the fact that over the long-term some 70 to 80 percent of patients either drop out of clinical trials or are in some degree noncompliant on antidepressants,

mood stabilizers, and antipsychotics, I pointed out the obvious: "Just sending a patient out the door with a prescription is not treatment."

I wasn't all negative. I mentioned how compliance rates could be improved upon by employing psychoeducation, support groups, various talking therapies, books, websites, and so on. But this did involve the need to

build trust with patients and spending time with them, plus being proactive in referring them to other services and sources of information. Again, just sending a patient out the door.

As soon as my lips stopped moving, the room emptied faster than a high

school Latin class at the three o'clock bell. No one approached me for a polite handshake or to follow up on any points I made, or to request more information. Only one person bought my book.

As I said, it is not my place to tell others how to do their job, particularly when nothing I said could be interpreted as a pat on the back, and my discomfort clearly showed in my talk. But even taking all of that into account, I was truly amazed by the magnitude of this group snub. Had I a PhD or an MD or an MSW to my name, I would have been treated with far more civility.

But I happened to be a journalist who was also speaking as a patient.

The biggest complaint I get from my readers, I said in my talk, doctors who don't listen. Boy, did they prove me right.

John McManamy
"Knowledge is Necessity
Musings on Mental Health"
January 5, 2009
www.mcmanweb.com



New Study Released on Prevalence of Serious Mental Illness Among Jail Inmates

The lead article in the June issue of *Psychiatric Services* by Henry J. Steadman, PhD and colleagues found that 14.5% of male and 31.0% of female inmates recently admitted to jail have a serious mental illness. The study was conducted by Dr. Steadman, and others. The authors analyzed data collected from two time periods at multiple jails to calculate the prevalence of mental illness. The screen was administered to 11,168 inmates during the first phase of data collection and 10,240 inmates during the second phase. These findings confirm what jail administrators already know – a substantial proportion of inmates entering jails have a serious mental illness and women have rates twice that of men.

July 2009

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NAMI

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in your Will

~

New Report Documents Housing Crisis Faced by Consumers Living on SSI

A report issued today demonstrates the deepening crisis in affordable housing faced by non-elderly adults living with serious mental illnesses. The report, *Priced Out in 2008*, is a study of the severe housing affordability problems of people with disabilities who must survive on incomes far below the federal poverty line.

The report compares the federal Supplemental Security Income (SSI) payments of people with serious and long-term disabilities to U.S. Department of Housing and Urban Development (HUD) Fair Market Rents for modestly priced rental units. *Priced Out* is published every two years by the Technical Assistance Collaborative (TAG) and the Consortium for Citizens with Disabilities (CCD) Housing Task Force (a coalition of national disability groups that includes NAMI) to shine a spotlight on our nation's most compelling — and least understood — housing affordability crisis.

In 2008, 219 housing market areas across 41 states had modest one-bedroom rents that exceeded 100 percent of monthly SSI, including 25 communities with rents over 150 percent. Between 2006 and 2008, the number of market areas with modest rents higher than SSI rose from 164 to 219 — a 34 percent increase. Perhaps the most shocking revelation in *Priced Out* in 2008 is the precipitous and relentless decline in housing affordability for SSI recipients since 1998 when the first edition of *Priced Out* was developed. The amount of monthly SSI income needed to rent a modest one-bedroom unit has risen an astonishing 62 percent from 69 percent of SSI in 1998 to 112.1 percent of SSI in 2008. The root cause of the nation's most severe — and most hidden — housing crisis is clearly revealed in the painful statistics included in the 2008 edition of *Priced Out*.

Supportive Housing Legislation Introduced

NAMI and our colleague disability advocacy organizations in the Consortium for Citizens with Disabilities Housing Task Force (CCD Housing Task Force) and the Technical Assistance Collaborative (TAG) are pleased to announce that important legislation to spur investment in permanent supportive housing legislation has been

introduced in Congress.

The bill, known as the Frank Melville Supportive Housing Investment Act of 2009 (HR 1675), was filed by Congressman Chris Murphy (D-CT) and Congresswoman Judy Biggert (R - EL). This ground-breaking legislation proposes important and significant changes and improvements to the U.S. Department of Housing and Urban Development (HUD) Section 811 Supportive Housing for Persons with Disabilities program.

The bill is named in honor of the late Frank Melville, a longtime member of NAMI Connecticut, and the first board President of the Melville Charitable Trust - a leading force in promoting supportive housing for people with severe disabilities. An identical version of the bill (HR 5772) passed the House unanimously in September 2008. Now efforts are underway to move the bill forward quickly in 2009.

Act Now!

Contact your House member and urge them to cosponsor HR 1675 using NAMI's Legislative Action Center. Tell them that people with disabilities need access to affordable, supervised housing!

To learn more about HR 1675 read more on the NAMI website, or visit the Technical Assistance Collaborative. ■

In Brief...

Hallelujah! In spite of the on-going comedy in the New York State Senate, our esteemed legislators have finally gotten their act together sufficient to pass legislation making Timothy's Law permanent, which has now been signed by Governor David Patterson.

Together RX is a new state program which can make medications more affordable for those without insurance and limited resources. For details go to TogetherRxAccess.com



Our Warmest Thanks to Our Donors and Members!

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