

Mark Your Calendar

July

NAMI Business Meeting, Thursday, July 3rd, 7:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. If you're a NAMI member, you're invited!

NAMI Family Meeting, Thursday, July 8th, Amherst Community Church, 77 Washington Highway, Amherst. Library and Hospitality Hour: 7:00 PM. General Meeting: 7:30 PM. Guest speaker: Judy Hyatt, PharmD, Veterans Administration Medical Center, on medication interactions.

NAMI Family Support Group, Wednesday, July 28th, 7:00 - 8:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. An evening of comfort and help for families struggling with mental illness.

August

NAMI Business Meeting, Thursday, August 7th, 7:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. All NAMI members welcome.

NAMI Family Meeting, Thursday, August 14th, Amherst Community Church, 77 Washington Highway, Amherst. An open meeting to tell your NAMI leaders what your greatest concerns and frustrations are (and to share your successes!). 7:00 PM

NAMI Family Support Group, Wednesday, August 25th, 7:00 - 8:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. Open to all family members with a mentally ill loved one.

September

NAMI Business Meeting, Thursday, August 7th, 7:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. All members welcome to attend.

NAMI Family Meeting, Thursday, August 14th, St. Paul's Lutheran Church, 4007 Main Street, Amherst. Note new location! Library and Hospitality Hour: 7:00 PM. General Meeting: 7:30 PM. Guest speaker: to be announced.

NAMI Family Support Group, Wednesday, September 22nd, 7:00 - 8:30 PM, NAMI House, 432 Amherst Street, Buffalo. For all family members with a mentally ill loved one.

October

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

NAMI's 20th Anniversary Celebration of Service, Friday, October 15th, Samuel's Grande Manor, 8750 Main Street, Williamsville. Keynote speaker, Prof. Gerard Hogarty, University of Pittsburgh, and Western Psychiatric Hospital and Clinic. Don't miss this very special evening!

NAMI Family Support Group, Wednesday, October 28th, 7:00 - 8:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. A healing place with folks who know what families go through.

NAMI Buffalo is on the Move!

Growth in our membership is a hallmark of the need for NAMI Buffalo's services—and for urgently needed improvements in the mental health system. But more new NAMI members has resulted in cramped quarters for our monthly educational meetings at Amherst Community Church.

So, beginning with our scheduled September 9th meeting, we'll be meeting at St. Paul's Evangelical Lutheran Church, 4007 Main Street in Eggertsville.

We have available a large parking lot behind the church, a much larger meeting room, and kitchen facilities adjacent to our meeting room.

Enter the church through the door facing the parking lot which has a handicapped ramp. The NAMI meeting room is on the second floor directly up the stairs as you enter the church.

We'll look forward to seeing you at St. Paul's in September.



Varieties of Schizophrenia

Researchers at the University of Pennsylvania have developed a new classification of schizophrenic patients based on memory disturbances and certain brain features. Researchers tested schizophrenic patients and controls for the ability to learn and remember. All subjects were also given MRI (magnetic resonance imaging) scans to observe brain structure and positron emission tomography (PET) scans to measure brain blood flow and energy consumption.

It turned out that the 245 patients could be divided into three groups. The first, including about 20% of the patients, consisted mostly of young men who developed schizophrenia early in life. Their symptoms included poor attention, disorganized thinking, and incoherent speech. Their memory deficits resembled Alzheimer's disease in some ways - poor recall, many false memories, and poor recognition memory. Yet they did not have particularly serious delusions or negative symptoms (apathy, emotional unresponsiveness). The temporal lobes of the cerebral cortex and the hippocampus, centers of emotion and memory, were smaller and less active than average. The authors call this the cortical type of schizophrenia.

A second group, which they call the subcortical type, comprised about a third of the patients. They also suffered from limited speech, poor attention, and disordered thinking, but their memory problems resembled Huntington's disease more than Alzheimer's — less memory loss overall, fewer false memories, and better recognition memory. However, this group had the most serious symptoms, both positive (delusions and hallucinations) and negative. Surprisingly, their brain activity, as measured by PET scans, seemed no different from that of normal controls. But their MRI scans revealed thinning in the gray matter of the frontal cortex, which governs planning, judgment, and initiative. Their temporal lobes looked relatively normal.

The third group, comprising 50% of the schizophrenic patients, had only mild memory problems. Their symptoms and brain abnormalities were a mix of milder forms of the features found in the other two groups. Yet they had more enlargement of the brain's fluid-filled cavities, the ventri-

cles (suggesting general atrophy of brain tissue), than the cortical group and more tissue loss in the temporal lobes than the subcortical group. This suggests to the authors that their classification represents real differences of kind and or origin, rather than just differences in the severity of schizophrenic symptoms.

*Harvard Mental Health Letter
March 2003*



NYS Senate Passes Weak Version of Timothy's Law

Following the Assembly's passage of Timothy's Law which would eliminate insurance discrimination against no-fault brain diseases, the Senate Republicans, on the last scheduled day of session, passes a weakened version of insurance parity. The Senate's version would eliminate coverage for companies of 50 or fewer employees, cover only a limited number of diagnoses, and provide no coverage for drug or alcohol problems. Tom O'Clair, Timothy's father, NAMI NY State, and a host of other organizations, as well as NAMI Buffalo--and you, we hope, will continue the fight.

Call your local senator today to turn up the heat! Leave the following message:

"I'm a registered voter in your district and I'm calling on you to urge legislative leaders to resolve remaining differences so that Timothy's Law can be enacted when the Senate and Assembly reconvene in July."

Sen. William Stachkowski	826-3344
Sen. Dale Volker	656-8544
Sen. Byron Brown	854-8705
Sen. Mary Lou Rath	633-0331

Also on the watch list:

The Senate has passed a PDL (Preferred Drug List) for Medicaid patients. If a doctor wishes to prescribe a drug not on the New York State list, he must go through the red tape of securing prior authorization. So far, medications used for psychiatric illnesses are generally exempt, but some used for mood disorders are not. We'll keep you posted on this very troubling development.

Oops!

We're sorry to have inadvertently omitted the designation of "MD" from NAMI's good friend and generous contributor, Linda Arzola. She is indeed a physician and psychiatrist, and we're honored to have her support.

New York's Most Integrated Settings Coordinating Council Medicaid Neutrality Cap is repealed

In June 1999, the United States Supreme Court rendered the landmark decision *Olmstead v L.C.*, 527 U.S. 581, which ruled that a state may be violating Title 11 of the Americans with Disabilities Act of 1990 if it does not place qualified disabled individuals into the most integrated community settings available. This case was hailed as the "Brown v Board of Education" for people with disabilities because the country's highest court finally declared that it is unacceptable for a state to unnecessarily institutionalize disabled people, thereby segregating them from the rest of society.

In his executive order on community-based alternatives for individuals with disabilities—part of the New Freedom Initiative issued in June 2001—President Bush ordered certain federal agencies to move toward the swift implementation of the *Olmstead* decision. Additionally, many states created "Olmstead Commissions" charged with determining what their states needed to do in order to be in accordance with the Supreme Court's decision.

In the fall of 2002, Governor Pataki signed into law the "Most Integrated Settings" bill, which created New York's version of an *Olmstead* Commission or, as it is officially called, "New York's Most Integrated Settings Coordinating Council." The Council is comprised of the Department of Health, Office of Mental Health (OMH), Office of Mental Retardation and Developmental Disabilities, Office of Alcoholism and Substance Abuse Services, Office for the Aging, Department of Transportation, Office of Children and Family Services, Department of Education and the Division of Housing and Community Renewal, representatives of the Office of the Advocate for the Disabled and the Commission on Quality of Care for the Mentally Disabled, three consumers of services for the disabled, three individuals who are recipients of services for seniors, and three individuals with expertise in community services for people with disabilities are also on the Council.

The new state law requires the Council to

develop and oversee the implementation of a comprehensive statewide plan for providing services in the most integrated settings to individuals of all ages with disabilities. The Council must provide a report of its plan to the Governor, the Temporary President of the Senate and the Speaker of the Assembly by December 16, 2003.

The Council would appear to be an important first step in finally ensuring that those people who would function optimally outside of an institution, adult home or nursing home receive treatment appropriate to their needs. Sadly, however, at least one regulation that remains on the books precludes the Council from fulfilling its goals: the Medicaid Neutrality Cap.

Created as an emergency measure during a budget dilemma in 1994, the Medicaid Neutrality Cap is a regulation promulgated by OMH that arbitrarily restricts the expansion or creation of mental health outpatient programs covered by Medicaid. That is, mental health service providers who propose new services have to identify the source of the state's share of Medicaid funding on their applications before OMH will grant the license. If the proposed service results in an increase in the expenditure of the state's share of Medicaid, then the application will be denied. There is no similar cap in effect for services provided by the Department of Health, the Office of Alcoholism and Substance Abuse Services or the Office of Mental Retardation and Developmental Disabilities.

In December of 1998, the Medicaid Neutrality Cap was reinstated on a permanent basis and not, as before, as an emergency measure. It is questionable how this regulation has survived in light of its obvious discriminatory implications. That notwithstanding, in light of the "Most Integrated Settings" law, it is logically incomprehensible how the state can continue to ensure that the number of mental health outpatient programs remain static while purportedly attempting to comply with a law requiring that disabled individuals be placed in the least restrictive settings.

Without an adequate number of outpatient programs to serve the needs of those who have been released from institutions and have opted not to reside in an adult or nursing home, people with disabilities will not receive the necessary assistance to reach their full potential in community settings. And as Governor Pataki has recently announced his proposal to close five state institutions in the next three years, the need to eliminate this restrictive provision seems greater than ever.

The mental health community looks forward to the release of the Council's first comprehensive statewide plan in December of this year. Meanwhile, the members of the Council, one of whom is a representative of OMH, the agency empowered to repeal its regulation, should begin by eliminating the Medicaid Neutrality Cap. This would certainly be a significant first step in realizing the mission of New York's Most Integrated Settings Coordinating Council.

Virginia Trunkes is an attorney and an active volunteer in NA MI-NYC Metro's Media and Advocacy Group.

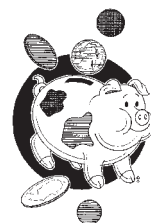
*Virginia Trunkes, Esq.
April 2003
NAMI-NYC METRO*

If You're a Tops Shopper...

Please remember to save your grocery and pharmacy tapes for NAMI Buffalo. Tops provides a rebate based on the dollar amount of collected tapes. Either bring them in with you to the monthly NAMI meeting or mail them to:

Barbara Rex
4129 Wildwood Dr.
Williamsville, NY 14221

Thanks!



Spitzer Sues GlaxoSmithKline Over Use of Antidepressant in Children

GlaxoSmithKline PLC committed fraud by withholding negative information and misrepresenting data on prescribing its antidepressant Paxil to children, according to a lawsuit filed Wednesday by New York Attorney General Eliot Spitzer.

The lawsuit, filed in New York State Supreme Court, said Glaxo suppressed four studies that failed to demonstrate the drug was effective in treating children and adolescents and suggested a possible increase of suicidal thinking and acts.

It also said an internal 1999 Glaxo document showed that the company intended to "manage the dissemination of data in order to minimize any potential negative commercial impact."

Glaxo spokeswoman Mary Anne Rhyne said the company "has acted responsibly in conducting the studies in pediatric patients and disseminating results. All of our studies have been made available to the (U.S. Food and Drug Administration) and regulators worldwide."

Rhyne also said the studies referred to in the suit have been made public in medical meetings, journals and letters to doctors. She said the internal document referenced in the suit "is inaccurate and inconsistent with the facts, and doesn't express the overall company position."

The lawsuit touches on two pharmaceutical and medical controversies: whether antidepressants increase suicidal tendencies in children, and if drug companies should be required to disclose all studies they conduct on their medicines.

Paxil is not approved for use in children, but doctors can prescribe drugs as they see fit and routinely recommend antidepressants for children suffering from depression and other psychological disorders. Only Prozac, which is made by Eli Lilly & Co., has been approved for use in children. According to Spitzer, Glaxo's revenues for Paxil prescriptions in children and adolescents totaled \$55 million in 2002.

The lawsuit seeks the return of all profits obtained by Glaxo as a result of conduct alleged in the suit.

*Theresa Agovino
America Online:
Sunday, June 06, 2004*

Timothy's Law Simply Seeks Parity

In a recent letter to the News, Paul Macielak, president of the Health Plan Association, stated that Timothy's Law is "a proposal to require unlimited insurance coverage of mental health and substance abuse services." This statement is misleading and untrue. Timothy's Law requires parity between coverages for physical and mental health services.

Macielak seems to be suggesting that to,ive mental health services parity is to make them "unlimited." He also stated that the increase in insurance costs associated with parity would make the cost of health coverage unaffordable to a larger percentage of New York businesses and individuals.

Contrary to this scenario, a 2003 study of Vermont's parity law. implemented in 1998, found that in the first two to three years, parity did not generally cause employers to drop coverage or switch to self-insured products and did not result in significant premium and health cost increases, despite the fact that Vermont's parity law is very comprehensive.

The problems addressed by Timothy's Law are real and consequential. Those with responsibility for providing information to businesses and consumers should be held to high standards of clarity and honesty when discussing issues of such importance.

*Douglas P. Easton
The Buffalo News*

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the challenger

Editor: Lynne Shuster

A Mother's Descent into Illness – and Tragedy

How a struggle with schizophrenia overcame a young North Buffalo woman — and apparently led to her baby's death

The photo of Kirsten M. Vanderlinde from 1993 shows a pretty, petite young woman, smiling as she looks up with bright blue eyes from the magazine she's reading. Sunlight frames her face and her flowing brown hair.

The photo of Vanderlinde taken May 28 appears to be of a different woman. Vanderlinde is heavy - she weighs 200 pounds - her curly hair is unkempt, her mouth is clenched in a frown, and her sad eyes are looking off camera.

The second photo is Vanderlinde's mug shot, taken at Police Headquarters, where the 36-year-old North Buffalo resident was charged with murdering her 7-month-old daughter, Melissa.

"It's almost impossible to believe," said Julie Moran Alterio, a close friend from college. "It is impossible to believe."

What happened in those intervening years? How did Vanderlinde - a vibrant university graduate and dedicated volunteer who spoke three languages, read the New York Times and studied in Europe - de cline into someone who carried on conversations at a pre-adolescent level and 10 days ago repeatedly slammed her baby onto a sidewalk?

The two images of Vanderlinde make sense in only one way.

Her decline was a descent into mental illness - schizophrenia. She had been able to control it through medication. But when she stopped taking the medication, about two weeks before the killing, she fell apart, according to several people close to the family.

"I don't want people to judge Kirsten as a monster, because she wasn't," said Shirley Ford, a close friend who lived in the same apartment complex for the past five years. "She's a person with a mental illness."

A private world

People who know Vanderlinde said she gave her baby love and attention and care. But two days before the killing,

Vanderlinde offered to give custody of her daughter to a friend in her apartment building. Neighbors also said she seemed mentally challenged, carrying on conversations at the level of a 10- or 12-year-old.

"When you stop taking your meds, you can start talking like you're a 10-year-old," said Mary Kirkland, local president of the National Alliance for the Mentally Ill. "You can sound like you could be developmentally disabled."



The photo above left shows Kristin M. Vanderline during her days at the University of Buffalo, where she was remembered as an exceptionally bright and thoughtful student. At right, her police booking photo.

Schizophrenia is characterized by a loss of connection to the outside world. Young people with schizophrenia may hear voices, experience severe delusions and hallucinations and often appear uncaring as they retreat into a private world.

That also may help explain Vanderlinde's behavior after the killing. When she was wrestled to the ground by police she was screaming: "I want my justice. Where's my justice? Where's my nice house? Where's my TV?"

Classmates and teachers at the University at Buffalo remember a different Vanderlinde. She was an exceptionally bright and thoughtful student who majored in French and German and was fluent in both, said Maureen Jameson, chairwoman of UB's department of Romance languages and literature.

Jameson, who taught Vanderlinde in several French classes, recalled a young woman who was wiry and full of energy and who had a political conscience. She spent two

semesters, fall 1989 and spring 1990, studying in Germany just after the fall of the Berlin Wall.

"She wasn't self-centered," Jameson said. "She was interested in women's issues. She was interested in political causes. She had a moral and ethical dimension."

Alterio, who lived off campus with Vanderlinde one summer, also said she's having trouble reconciling her friend with the accused baby killer.

Alterio spoke last week to a relative of Vanderlinde's who recalled that she always took the time at the grocery store to compliment the cashier on her outfit or her appearance.

When this relative once went through the line at the store with only a "thank. you" for the cashier, Vanderlinde said he needed to be nicer, Alterio said.

"It was something she did naturally," said Alterio, who now lives in Westchester County. "She always saw the essential humanity in people."

Diagnosed in Mid-20s

Vanderlinde grew up in Ithaca, where her father was a schoolteacher. At UB, she enjoyed exploring off-the-beaten-path parts of the city in her Birkenstock clogs, and she chose to stay here after graduating. She had a curiosity about other cultures and other people, Alterio said, and read the Times for news of the wider world. Vanderlinde introduced her friends to new foods, preparing dishes like gazpacho in a big green ceramic bowl.

But during college, her illness began to take effect. Vanderlinde first noticed symptoms when she had trouble concentrating on her studies. Eventually, she was diagnosed with schizophrenia in her mid20s; that's typical of the illness, which usually strikes people in their 20s or early 30s. Her mother also suffers from the illness, and having a schizophrenic parent is considered a highly significant risk factor, mental health experts say.

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But she was so determined that she would n't quit school, taking seven years to complete her degree.

Shortly after graduating in 1994, Vanderlinde worked for a time as a substitute teacher.

When she realized she couldn't handle the demands of teaching full time, she turned her energies to volunteering and helping people, including working with Meals on Wheels and as a health care aide, Alterio said.

Those who knew Vanderlinde said that even as recently as weeks ago, while still taking all her prescribed drugs, she kept a tidy house and cared lovingly for her daughter, who they said often smelled of fresh baby powder. She had become more religious in recent years and during difficult periods would ask friends to pray for her.

Vanderlinde and her boyfriend, Anthony S. Berst, lived together in their Kenmore Avenue apartment for the past six or seven years, said Ford, who lives in the same complex.

Berst has a minor criminal record for marijuana possession and other charges. He also has mental problems and was supposed to be taking medication for treatment, Ford said.

The couple had an on-again, off-again relationship. And Vanderlinde confided in Ford that she was afraid of Berst, but she also talked about marrying him this fall - around the time of Melissa's first birthday. Vanderlinde also told Ford she wanted to have another baby, because Berst wanted a son.

After Vanderlinde became pregnant early last year, she went off at least some of her medication because she feared it could harm her unborn child, several sources said. She also stopped taking her medication several other times, deciding on her own that she didn't want to take it, Ford said. More than once, paramedics took her to Erie County Medical Center or Buffalo General Hospital.

"She'd be suicidal. She'd become real agitated.... She was a totally different person when she was off her medication," Ford said.

After giving birth, Vanderlinde went back on her medication for an extended period, but stopped taking some of the drugs about two weeks before the killing. Family members and local mental health officials want to know whether a doctor approved of her not taking some of her drugs.

Now she's charged with second-degree murder in a beating death that horrified the community.

'Acting out her anger'

So what happened two Fridays ago? Her defense attorney, John R Nucheren, has his own theory. "She loved her baby and cared for her baby," he said. "But in her own mind, I believe she felt she had no control over her baby. She didn't understand she was doing a beautiful job with her. She was just acting out her anger and frustration that she couldn't be the world's best mother. She didn't know that she was harming the child.

"It's not supposed to make sense," Nucheren added. "It's not something we understand."

But it does make sense to those who have lived with the behavioral changes among some schizophrenic patients.

"This was so totally out of character, such a dramatic change," Kirkland said of Vanderlinde's behavior that day. "Obviously, what changed is that she stopped taking one of her medications."

Vanderlinde's next court appearance has been postponed from Monday until June 18, because forensic mental health doctors say they need more time to properly evaluate her after she becomes stable on her medication.

Nucheren has visited with his client, and he fears how she will react when she understands what has happened. That's why she has been placed under a suicide watch. "She's slowly coming to grips with what she actually did," he added. "It's going to hit her hard, and everyone knows it."

*Stephan Watson and Gene Warner
The Buffalo News
June 6, 2004*

Free Radicals Linked With Treatment Resistance

PHILADELPHIA, Pennsylvania

Cell damage caused by free radicals could explain why some people with schizophrenia don't respond to treatment, according to new University of Pennsylvania research.

The study, published in the April edition of the American Association for Geriatric Psychiatry, found evidence of a destructive biological process similar to that seen in people with Alzheimer's disease and other major neurodegenerative disorders.

Free radicals are naturally occurring chemicals in the body that have been linked to a variety of health problems. In the new study, researchers conducted testing on the brains of deceased elderly people who had schizophrenia and who hadn't responded well to treatment, and compared it against the brains of deceased elderly people with no known psychiatric disorders.

The brains of those with schizophrenia showed far greater indication of "oxidative DNA damage," something that occurs when free radicals overwhelm a cell's antioxidant capabilities, the researchers say.

This damage was evident in neurons located in a part of the brain called the hippocampus, which is associated with complex memory activities. The number of neurons with evidence of this damage was 10 times higher in the brains of those with schizophrenia than in those without the disorder.

The study was headed by Dr. Naoya Nishioka and Dr. Steven Arnold with the university's Cellular and Molecular Neuropathology Program, in the department of psychiatry's Center for Neurobiology and Behavior.

*Schizophrenia Digest
Spring 2004*



And do not those with mental illnesses also bleed?

Editor's note: NAMI friend Judge Max Higgs quoted The Merchant passage, below, as he spoke to those gathered for last year's NAMI El Paso annual candle-light vigil. Judge Higgs of the El Paso County Probate Court handles that city's mental health cases and conducts cases in a psychiatric center. More than willing to take a public stand for people with serious mental illnesses, he speaks with conviction and eloquence a truth more should hear.

From a presentation by Judge Max Higgs, El Paso, Texas The following is the essence of Judge Higgs' address:

He hath disgraced me and hindered me, laughed at my losses, mocked my gains, scorned my nation, thwarted my bargains, cooled my friends, heated mine enemies, and what's his reason? I am a Jew. Hath not a Jew eyes? Hath not a Jew hands, organs, dimensions, senses, affections, passions? ...If you prick us, do we not bleed? If you tickle us do we not laugh? If you poison us, do we not die? With these words from *The Merchant of Venice*, William Shakespeare raised questions that are always present when people live in close proximity to each other while not living in community with each other. Dominant, privileged cultures—whether it be the European American in relation to the Native American or white Americans in relation to African Americans or English-speaking Americans in relation to those who speak other languages—have always had difficulty understanding and dealing with the humanity of those who have been in some kind of internal exile, be it in the ghetto or the mental hospital.

Too often and too long, the mentally ill in America have been banished to remote, rural state hospitals or left to languish in motels, shelters, and programs whose standards do not rise to the level of a proper stable or kennel.

Hath we not laughed at their losses? Have we not mocked their gains? Have we not made the mentally ill the butt of our jokes and ridiculed their disease-induced follies? Have we not scorned their nation when they tried to move into decent housing in our neighborhoods?

And for what reason? Not because they are Jews or people of color, for we are too progressive to act that way in this enlightened time. Of course not, when our conservatives are compassionate and our liberals are reasonable. Then for what reason? Hath not the mentally ill hands, organs,

dimensions, senses, affections, passions? If you prick the hand of a person with a bipolar disorder, will he not bleed? If you tickle the ribs of the mentally ill, do they not laugh? Don't the mentally ill love their parents and their siblings? Don't they have the pain that comes from love gone wrong just as you and I? If we put them in substandard housing where drug dealers and sexual molesters prey them up, if we leave them to be infected with HIV and bad drugs, are they not poisoned and thereby die?

The questions raised by *The Merchant of Venice* confound us as much as they did Shakespeare's audiences centuries ago. Are we to treat the differences among us as barriers to divide us, or shall we treat those differences as challenges to unite us in our humanity and as blessings that enrich our diversity?

Consumers and advocates must become more proactive in the political and governmental process. It is time to speak up and perhaps even time to act out, but whatever you do, you must not give up.

We must challenge our community leadership to see that mental health treatment programs are an economic boon to the community and not an economic drag. But even more important than economic benefit, we must provide for the mentally ill because it is the right thing to do.

It is time for consumers and advocates to stop enabling dysfunctional systems. It is time to end outrageous practices that resulted in having a non-Spanish-speaking patients' rights officer in this very psychiatric center.

It is time to realize that there are no innocent bystanders among governmental officials. There are only those who will help and those who would be obstacles to progress.

It is time for public leaders... to realize that there is more expected of them than merely nominating someone, anyone, to the board of the mental health authority. But maybe mental health is not that important. Maybe mental health is just not important enough for us to change the way we do business. I can tell you that mental health services are not that important... unless you are like the mother who told me this week that her son was arguing with the voices of his illness and he was saying, "No, no, I will not kill my mother." Mental health is not that important unless you are like the father who came to court and told me that he would be responsible for his son and who took that son

home that morning and that afternoon the son said, "Dad, I am going to go mow the lawn for you." The son went out and poured the gasoline over himself and burned himself to death.

Mental health will not be that important to you perhaps until your son climbs to the top of a four-story building and, in response to the voices he hears, jumps and breaks his back.

Mental health might become important to you if it is your son who escapes from the mental health authority and injects himself with cocaine while out with another consumer. Thirty days later his HIV test was negative, but 60 days after that, it was positive. Gene died 14 months ago, not even 25 years old and with a genius-level IQ.

Maybe mental health will become important when it is your grandchildren who are living in a home made dysfunctional by mental illness. Maybe mental health will become important to you when it is your children who are riding in a small car with a neighbor who could no longer deal with her depression and aimed the car in front of a truck moving at high speed.

We have heard from *The Merchant of Venice*. Let us listen to a son of Abraham. King David in the 31st Psalm captures much of what I understand to be the effects of mental illness:

*Be merciful to me O Lord, for I am in distress,
My eyes grow weak with sorrow,
My soul and my body with grief.
My life is consumed by anguish
And my years with groaning My strength
fails because of my affliction,
And my bones grow weak. Because of all my
enemies, I am the utter contempt of my
neighbors....
For I hear the slander of many,
There is terror on every side, They conspire
against me And plot to take my life.*

It sounds to me that, to the extent we can alleviate suffering as described by the Psalmist, we are instruments of the mercy of God.

So there we have it. Providing quality services to the mentally ill is to comply with the law of the land. It is to engage in enlightened social policy. It is to be humane. And even more, it is to transcend the realm of humane behavior and to partake of a divine nature.

From Jail to Reintegration: Bridging the Gap

The heavy metal door swings open and a newly released jail inmate, we'll call him Hank, shuffles haltingly into the light of day. Hank suffers from schizophrenia and has an alcohol problem too. He had been arrested for walking aimlessly in traffic.

Hank's time and society's justice have both been served, and now he's free. But will Hank stay free? Or, will he become part of the vicious cycle of recidivism that ensnares Hank and so many consumers like him, leading them right back to unacceptable behaviors and jail? Many inmates with co-occurring disorders, men and women both, have cycled in and out of jails and prisons countless times.

Without a plan and community support for his reentry into society, Hank faces tough times on the outside. Housing restrictions often apply to people released from the criminal justice system. Workplace restrictions often apply too since felony records can disqualify employment in some occupations. Then, of course, there are the many informal restrictions as a result of the prejudice against former offenders.

It's no wonder then that Hank may soon be overwhelmed by his "freedom" and face a host of problems: more mental illness symptoms, relapse to substance abuse, suicide, homelessness and certainly, re-arrest and further incarceration. The fact is, Hank never received any discharge planning in jail, the least frequently provided mental-health service within jails and prisons.

But now, consumer advocates, researchers and government agencies are taking action to short-circuit the prison's revolving door and get these consumers reintegrated. Tom Lane, head of Consumer Affairs for NAMI, and his colleague, attorney Ilisa Smukler, have, in collaboration with the Broward County Department of Children and Families, the Broward Regional Health Planning Council, the ADM Planning Council and the Broward Office of Consumer Affairs begun a program in Broward County, Florida designed to train consumers to help other consumers who have been released from jails and prisons.

"There are terrible risks and hurdles confronting newly released consumers," said

Lane, "and they need a trained person to help them navigate these tough waters."

The peer bridgers are consumers who may have been imprisoned themselves at one time. They will bring to bear their experiences and now, their training to the released consumer who needs to succeed in society. If the program is adopted nationally, the potential benefits to society are great. Three out of every hundred American adults are under some form of correctional supervision, either in jails or prisons, or else on probation or on parole. Like Hank, around half a million of these people also have severe mental illnesses, such as schizophrenia, along with a co-occurring substance abuse problem.

"Dreams don't have limits. When given the proper support, people can achieve their dreams."

According to The National GAINS Center, an organization that studies people with co-occurring disorders in the justice system, the rate of current severe mental disorder was 6.4 percent for male detainees entering jail and 12.2 percent for female detainees. And, three-fourths of these people have a co-occurring substance abuse disorder. Our jails have become surrogate mental hospitals. The Los Angeles County Jail alone holds more people with mental illnesses than any state hospital or mental health institution in the country.

A person's stay in a jail or prison costs society from \$70-400 a day depending upon the level of security measures involved. The number of stays can be dramatically lowered with the new program, resulting in huge cost savings to society.

The story of the peer bridger curriculum began almost a year ago. Pat Kramer, Program Supervisor for Alcohol, Drug Abuse and Mental Health of the Florida Department of Children and Families (DCF) in Broward County, Florida, along with her colleague Valerie Allen, was well aware of the recidivist problem. The two wanted to formalize a certification process for peerto-peer counselors that could help consumers caught in the criminal justice system bridge the gap between jail and society.

Kramer and Allen approached Lane and Smukler who were running a highly regarded drop-in center at South Florida State Hospital, in Pembroke Pines, Florida. The drop-in center already employed consumers to work with other consumers, so it seemed a logical step to ask Lane and Smukler how their program might be extended to the criminal justice system.

The logic proved to be sound. Lane and Smukler went to work studying a number of related programs around the country, most notably in New York and California. They held focus groups with consumers and consulted with many mental health agencies and researchers. Within six months, Lane and Smukler developed a six week, 90 hour course that not only trains consumers to be peer bridgers, but can also train them to train others.

"Our curriculum integrates a number of models and many perspectives," said Smukler. "Tom's very familiar with mental health policies and practices, while I, as an attorney, know the kinds of forensic issues offenders face. We were able to embed into the curriculum our own experiences along with the perspectives of many others, including the DCF people and various researchers. We also stress in the curriculum the importance of having peer bridgers know the local resources available for the newly released consumer."

The first half of the course, in the first three weeks, consists of general mental health and substance abuse topics, including community resource awareness and basic helping skills for recovery. The second 45 hours of training over the following three weeks focus on forensic topics, including the intersections of

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the mental health and criminal justice systems, community reintegration for mentally ill offenders and strategies for success.

Special problems addressed in the course include suicide, crisis intervention, competency restoration, ethics and confidentiality and liability.

One of the models used to create the curriculum was the so called APIC model of the GAINS Center. APIC is an acronym representing the main steps to be taken by peer bridgers:

Assess the inmate's clinical and social needs, and public safety risks.

Plan for the treatment and services required to address the inmate's needs. Identify required community and correctional programs responsible for postrelease services. Coordinate the transition plan to ensure implementation and avoid gaps in care with community based services.

As the GAINS APIC report on best practices for community reentry states, "Transition planning can only work if justice, mental health, and substance abuse systems have a capacity and commitment to work together."

One of the hallmarks of the APIC process incorporated into Lane and Smukler's curriculum is an emphasis on engaging consumers in the process from the earliest stage possible in understanding their own transition needs, and then building a transition plan that meets those needs.

"This curriculum helps consumers to empower themselves so they can recover and regain their ability to dream," says Pat Kramer of DCF. "Dreams don't have limits. When given the proper support, people can achieve their dreams."

"While the program will begin in Florida, it's highly portable, and will be applicable to any consumer, anywhere in the country," said Lane. "True, there will be a big variation in the resources available from one location to another, but the principles will be the same. And the main underlying principle is, we're training people to be an advocate and a friend.

Reintegration Today
Summer 2003

Depressed? Hold on to Your Benefits

The state welfare agency cannot penalize welfare recipients with mental illnesses for missing appointments or paperwork deadlines, according to a recent court decision.

A few weeks ago, the New York State Appellate Court ruled in favor of Juana Diaz, a Manhattan resident who lost her public assistance in January 2001 after she failed to respond to a request for information about her income from the state Office of Temporary and Disability Assistance (OTDA).

Diaz argued that she forgot about the form and missed the deadline because she is clinically depressed. A medical report she presented to the state explained that she is "easily overwhelmed" and "acutely depressed and dysfunctional." Still, the state would not reinstate her benefits, arguing that depression is not a medical condition, and that decision was upheld at her fair hearing.

The state appeals court saw it differently, however. If a welfare client can show "good cause" for failing to comply with certain requirements, state law says, that client is exempt from those mandates. Good cause, the panel of judges pointed out, includes physical or mental conditions such as clinical depression. This ruling sets a precedent for people with mental disabilities, and could affect hundreds of New Yorkers on welfare. A study published in February 2000 by the Center on Budget and Policy Priorities estimated that "roughly one-fourth to one-third of current [Temporary Assistance for Needy Families] recipients have a serious mental health problem."

In New York City, that would mean between 44,000 and 59,000 clients. (The Human Resource Administrations reports that 176,311 adults received benefits in February of this year.)

The Appellate Division also offered a surprisingly stinging rebuke of the OTDA. "Regrettably, this is not the first time we have found that an administrative agency ... has used a person's incapacity against her." A spokesman for the OTDA declined to comment.

Marley Seaman marleynclimits.org

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What is a Chemical Imbalance?

People suffering from mental illnesses or brain disorders are frequently told that they suffer from a chemical imbalance in the brain. What does that mean? In order to understand what a chemical imbalance is, it is necessary to have some general idea of how the brain works.

The brain is the organ in the body that is responsible for thoughts, feelings, and control of virtually everything that we do. The brain is organized into clusters of cells, each located in different areas of the brain. Each cluster is responsible for different functions. So, for example, the ability to produce speech occurs in one part of the brain and the ability to understand speech takes place in another part of the brain. In order for our speech to be reasonable what we say must be related to what we hear. Therefore, these two parts of the brain must be able to communicate with each other.

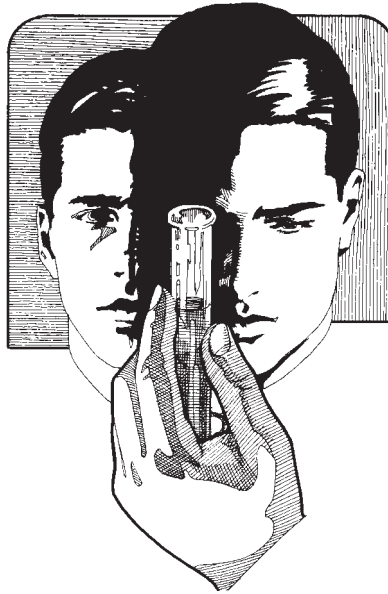
If this communication between the parts of the brain is interfered with, there would be a significant impairment in our ability to make both understand and make ourselves understood. Nerve cells perform this task of linking different parts of the brain together by a process known as neural transmission. One way to understand the brain depends on where problems are taking place. Another way of understanding the brain is to understand how these parts of the brain are communicating with each other.

One kind of chemical imbalance will have something to do with the balance between actions that are taking place in different parts of the brain. Another kind of imbalance will have something to do with how nerve cells carry messages. In order to understand either of these we have to understand how nerve cells work.

Nerve cells move information from one place to another. Each cell is made up of many, highly specialized parts, but to simplify things, we will look at only four: a part that receives information; a cell body where cell metabolism takes place; an "axon" that moves the message over great distances; and a transmitting end, the part of the cell that passes information on to the next cell. In general, information moves

only one way: from the receiving end, through the length of the cell body and axon to the transmitting end. Neural transmission, i.e., nerve cell communication, is an "electrochemical" event. This means that nerve cells transmit information by means of a series of both electrical and chemical changes.

The "electro-" refers to how information moves across the cell. We can observe this



small electrical charge that nerve cells create when they carry messages when we do an EEG (electroencephalograph). Many of the medications that are used to treat seizures and bipolar disorder influence this "electro" part of the electrochemical event. So, medications such as valproate (Depakote) or carbamazepine (Tegretol) modify the movement of messages across the length and breadth of the nerve cell. We believe that these medications do this by stabilizing the cell membrane which then blocks the electrical passage of information and thereby slows down neural transmission. The "chemical" part refers to how messages move from one cell to the next.

When two nerve cells meet they do not touch but are separated by a small space called the synapse. Most psychiatric medications work by modifying what goes on in the synapse. This is the place where we presently can best find and influence the chemical imbalances associated with men-

tal illnesses. Obviously, the synapse, the space where nerve cells meet will be a very important space to understand.

The synapse consists of an incoming nerve cell. (the presynaptic nerve cell), a small fluid filled space across which chemicals will drift, (the synaptic cleft), and an outgoing nerve cell (the postsynaptic cell) that receives the message and carries it forward to the next cell. The chemicals released by the incoming, transmitting, presynaptic cell are called neurotransmitters. These message carrying chemicals, the neurotransmitters, drift across the synaptic cleft and attach to special parts of the receiving, postsynaptic cell, called receptors. When enough of the receptors are stimulated, the postsynaptic cell "fires" and carries the message forward.

When we speak of a chemical imbalance we are talking about an imbalance in the chemicals that carry messages between cells such that they do not perform their message carrying function properly. There are several kinds of difficulties that could cause an imbalance.

The kind and amount of neurotransmitters that are released by the presynaptic cell can be out of kilter. Something can happen to the neurotransmitters as they drift across the synaptic cleft so that they no longer are as effective. The neurotransmitters can interact with the receptor on the receiving, postsynaptic cell in a peculiar way such that the message is interfered with. There are many other types of problems that can influence this tightly controlled and delicately balanced system. This should not be surprising. The more delicate and complicated a system is, the more easily it is to disturb it. While the brain is well protected, by bone and special membranes, it is not invulnerable.

An example of the problems associated with correcting chemical imbalances may help. Dopamine is an important neurotransmitter that is used in many different cell clusters in the brain. Even though each cluster uses dopamine as its neurotransmitter to move, each cluster is responsible for a different behavior. In the cluster known

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as the striatum, dopamine is involved in the control of movements, in the frontal lobes, dopamine plays a role in attention and concentration, and in the meso-limbic system dopamine plays a role in psychosis. Clearly, if there is an imbalance in dopamine there can be problems in any or all of these functions.

It would be simple if all of the problems were the same, that is, too little dopamine in each area. Then we could give medications that could only raise the level of dopamine everywhere. Unfortunately, this is not the case. Dopamine requirements and balance are different in different parts of the brain. Too little dopamine in the striatum causes the symptoms of Parkinson's disease but too much dopamine in the meso-limbic system can cause psychosis. Physicians can help minimize the resultant movement problems of Parkinson's disease by giving a medication such as LDopa (sinemet) which will raise dopamine levels wherever dopamine is found, including areas where it may be normal and where we do not want it raised.

This may correct the movement problem of Parkinson's disease but cause psychosis. Similarly, we can treat the problem of psychosis by giving medications such as fluphenazine (prolixin). This will lower dopamine levels everywhere dopamine is found including areas where it is normal and where we do not want it lowered. This may help correct the problem of psychosis but can cause the person to have problems with the control movement, i.e., the symptoms of Parkinson's disease. When this happens we say that the person is having side effects.

Chemical imbalances are complex and their treatment is not without problems. In the future, a few things are likely to occur. We are likely to develop a better picture of how nerve cells communicate with each other and how different parts of the brain work. Moreover, it is likely that better medications will be developed to address the brain disorder problems that are caused by chemical imbalances and their treatment.

Mental Health News - Summer 2003
Richard H. McCarthy MD., CM, Ph.d.
Comprehensive Neuro Science

Increased Risk for Schizophrenia Seen in Rh Positive Babies Born to Rh-Negative Mothers

Results of a new study carried out at the University of California, Los Angeles, provide further evidence to suggest that babies with Rh-positive blood, who are born to mothers with Rh-negative blood, are at increased risk for developing schizophrenia. These findings are especially important, because the condition, known as maternal-fetal Rh incompatibility, creates a risk factor that is potentially preventable.

"We have reliably effective pharmacological means to block an Rh-factor incompatibility," says Christine GS Palmer, MD, an assistant professor of psychiatry and biobehavioral sciences at UCLA and the study's principal investigator.

Three earlier studies had implicated Rh incompatibility as a potential risk factor for schizophrenia. When the mother is Rh negative, she has no protein in her blood coded for by the RHD gene. If the fetus is Rh positive, the mother's immune system may mount a response to the RHD protein, which it perceives as foreign. That response can have drastic effects on the fetus, including fetal hypoxia (reduced oxygen) and anemia, and an increase in unconjugated bilirubin, a known neurotoxin to which developing cells of the central nervous system are sensitive. Previous research has linked fetal hypoxia and abnormal glial development to increased risk of schizophrenia.

In the current research, Dr. Palmer and her colleagues studied the RED genotypes of 181 individuals with schizophrenia or schizoaffective disorder and their parents. All of the patients had been born before there were pharmacological means available to block an Rhnegative mother's immune-system response to her Rhpositive fetus. (The first such product, RhoGAM immune globulin, was developed in the 1960s.) What they found was an over-representation of combinations in which the mother was Rh negative and the child was Rh positive, amounting to a two-fold risk. Dr. Palmer says that her study does not imply that the RHD gene causes schizophrenia. Rather, it acts as "a trigger that sets up a cascade of events that results in

an increased risk" of developing the disorder. "This is a risk that is due to an adverse fetal environment, not a gene that is acting directly on the individual fetus's body to cause schizophrenia. And it is a risk that is reducible."

"RH Maternal-Fetal Genotype Incompatibility Increases Schizophrenia Susceptibility" by Christina G.S. Palmer, MD, et al., in American Journal of Human Genetics, December 2002, and "Rh Incompatibility May Be Schizophrenia Risk Factor" by Jim Rosack, in Psychiatric News, 12/20/02



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British Institute Publishes New Guidelines for the Treatment of People with Schizophrenia

In early December, Great Britain's National Institute for Clinical Excellence (NICE) published a set of guidelines that delineate what is judged to be best practice for health professionals who care for individuals with schizophrenia. The guidelines were developed jointly by a committee of health professionals and people with schizophrenia, under the chairmanship of Tim Kendall, M.D.

First of all, the guidelines emphasize the need for shared decision-making and informed consent in all aspects of schizophrenia care. "Health professionals should work in partnership with service users [patients] and caregivers, offering help, treatment, and care in an atmosphere of hope and optimism." The nature of schizophrenia can make it difficult for people to make informed decisions about their treatment, "but health professionals should make all efforts necessary to ensure that a patient can give meaningful and properly informed consent before treatment is started."

With regard to medications, the guidelines state that any medicine used in treatment should be chosen jointly by the patient and the clinician. Atypical antipsychotics at the lower end of the standard dose range should be considered in the choice of first-line treatments for individuals newly diagnosed with schizophrenia. Moderate doses of antipsychotics are recommended in order to avoid the use of high doses and loading doses that are sometimes used. People with schizophrenia should take only one antipsychotic at a time, except in rare cases. Dr. Kimball noted that nearly half of all people being treated with neuroleptics [in England and Wales] are currently taking more than one drug. "There is no evidence that this is beneficial for most people," he warned.

"Antipsychotic drugs are an indispensable treatment option for most people in the recovery phase of schizophrenia," the guidelines advise. "The main aim here is to prevent relapse and help keep a person

stable enough to live as normal a life as possible. Drugs are also necessary for psychological treatment to be effective."

Psychological treatments, particularly cognitive behavior therapy and family interventions, were also recommended as an indispensable part of treatment for patients with schizophrenia and their families. They should be used "to prevent relapse, reduce symptoms, increase insight, and promote adherence to medication." According to the guidelines, anyone with psychotic symptoms should be offered at least 10 sessions of cognitive behavior therapy. "Longer treatments are significantly more effective than shorter ones, which may improve depressive symptoms but are unlikely to improve psychotic symptoms."

"People with Schizophrenia Must Have a Say in their Treatment" by Susan Mayor, in the British Medical Journal, 12/07/02, and "Core Interventions in the Treatment and Management of Schizophrenia in Primary and Secondary Care," published by the National Center for Clinical Excellence, and available on the Web at www.nice.org.uk



From devastation to power: NAMI's Family-to-Family course

"Family members who take the NAMI Family-to-Family course are better equipped to work with mental health clinicians in a collaborative manner. My bottom-line recommendation? Take the course. It will help you learn to cope successfully with a major challenge in your life, and that, in turn, will help your loved one as he or she works toward recovery."

Peter Weiden, M.D., author of Breakthroughs in Antipsychotic Medications

Family members and friends who are self-aware and armed with the most solid information about mental illness are better equipped to advocate successfully for their ill loved ones. They are better prepared to deal with the ups and downs inherent in mental illness. And they tend to have more meaningful relationships with their children, siblings, partners and friends who suffer from a psychiatric disorder. These are the ideas from which the NAMI Family-to-Family course has emerged. First developed by NAMI-Vermont in 1990, the NAMI Family-to-Family course is now taught by over 2,000 trained NAMI volunteers in 43 states, four large municipalities and two provinces of Canada. The free 12week course is taught by local family members who help participants identify the resources-both external and internal-that can help them handle the challenges of having a close family member or friend who suffers from a mental illness.

The course explains the symptoms of and treatments for schizophrenia, major depression, bipolar disorder, panic disorder, obsessive-compulsive disorder, borderline personality disorder and co-occurring brain and addictive disorders, and provides up-to-date information on medications. Participants, some already self-taught "experts" themselves, exchange ideas and strategies for maximizing access to appropriate services.

Perhaps most important, the course provides support. Family members and friends take time to explore the pain and trauma they have experienced as individuals closely involved with someone struggling with a serious mental illness. In the process, participants develop close-knit friendships, and even after the course ends group members typically continue to meet in a support group environment. NAMI-Buffalo offers the Familyto-Family course at least two times a year, usually in the spring and in the fall. To learn more about the course or to sign up for the next session, please call 877-2076

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