

Boot the SHU

Bill seeks to ban use of special housing units for inmates with mental illnesses

by Leah Gitter

Imagine yourself spending months, or even years, isolated for 23 hours a day in a poorly lit concrete cell that measures 56 square feet. Imagine having negligible human contact and no programs or activities to occupy your time. Imagine being fed through a slot in a thick metal door. Imagine being controlled by corrections officers uneducated about mental illness. Imagine not getting any treatment for your condition no matter how much despair you feel. Imagine being fed "the loaf" -- a one-pound loaf of bread made primarily of yeast, flour and potatoes -- with a side portion of cabbage three times a day.

These forms of punishment sound like something out of a Dickens novel, but they're not. Each day, over 1,000 New Yorkers with psychiatric disabilities are housed in Special Housing Units (SHU)

in prisons throughout New York State. And while these conditions would be harmful to anyone's mental health, the damage done to people with psychiatric disorders is immeasurable.

Fortunately, there are signs of hope that this barbaric practice may soon come to an end. In June 2004, Bill A8849 was passed in the Assembly of the New York State Legislature. This bill, introduced by Assemblyman and Chairman of the Corrections Committee Jeffrion Aubrey (D-Queens), makes placement of prisoners with psychiatric disabilities in SHU illegal and requires that appropriate housing be provided for this population within the New York State Department of Correctional Services. The bad news, though, is that Bill

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Breaking the Deadlock

Family psychoeducation bridges gaps in communication between consumers, providers and family members

by Judith Carrington

When mental illness occurs, family members may have little knowledge or understanding of what their loved ones are experiencing. In frustration and ignorance, they may even turn their backs on the ill person, leaving the consumer to feel betrayed and abandoned.

Mental health providers, meanwhile, may tend to define their cases by symptoms, often approaching the consumer in a way that makes him or her feel invalidated.

And though family members will be told by providers that they are part of

the treatment team, they often feel excluded and marginalized in the name of patient confidentiality.

Though these communication gaps may seem insurmountable, one treatment in particular has proven to profoundly affect the course of mental illness while building a partnership of trust and empowerment between all parties. It's called Family Psychoeducation (FPE).

Through dynamic participation, consumers, family members and

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Timothy's Law: Can we afford it? How can we afford to live without it?

by Wendy Brennan



Timothy's Law supporters in Albany on November 18.

On November 18th, 2004, the day that the New York State Senate returned to Albany from recess to finish out the 2004 legislative session, our senators were greeted by hundreds of enthusiastic supporters of Timothy's Law. Mental health advocates came to Albany from New York City and around the state to rally in front of the Capitol for the passage of mental health parity legislation.

It may have been a gray, chilly November day but the weather didn't seem to dampen the spirits of the

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FROM THE EXECUTIVE DIRECTOR

EVELYN ROBERTS, PhD.



ASK THE DOCTOR

Dealing with Chronic Mental Illness: How Families Can Help

by Martin S. Willick, M.D. Lecturer in Psychiatry, Columbia University College of Physicians & Surgeons

The state of psychiatric care was quite different when I began my training at the Albert Einstein College of Medicine in New York in 1959. Thorazine had been introduced only four years before and anti-depressants were just starting to be used. Very few psychiatrists were interested in studying and treating the most severe mental illnesses like schizophrenia and manic-depressive disorder because we knew so little about them.

Things have changed a great deal since those days. Since then we have shown that schizophrenia and bipolar illness are caused by a number of biological abnormalities and, although we still do not have a cure, we now have medications that can really make a difference in the course of these diseases.

One of the greatest social changes has been the way we view the parents of those with chronic mental illness. They no longer blamed and feared by mental health professionals. Rather, they are often included in the treatment process and have become important allies to those professionals.

It is no easy task for the families of the chronically mentally ill to offer help to their loved ones. Parents and siblings often go through such anguish and torment as they watch their loved ones become ill that they themselves need help in coping. Therefore, it is important for us in the mental health field to understand and recognize the complex array of emotions experienced by family members.

Mourning and Loss

If a person with schizophrenia has

particularly severe negative symptoms involving lack of motivation, inability to experience pleasure, decreased speech and spontaneous movement, there results a loss of a certain kind of emotional connectedness between the ill relative and his or her family members. It becomes difficult for the ill child to experience affection or communicate effectively with his or her family. Loved ones, thus, often grieve the loss of the way things once were. So even though the child is still alive, the experience is not unlike the mourning that occurs after the death of a child.

Guilt

Even if family members understand intellectually that schizophrenia is a biological illness, it is very common for them to experience feelings of guilt. Parents may blame themselves for possibly passing on a defective genetic trait, while others dwell on their perceived past failures that they imagine contributed to the child's stress. Many siblings, meanwhile, have what can be described as "survivor guilt," in which they feel guilty that their brother or sister is the sick one, rather than themselves.

Anxiety and Fear

Among family members, anxiety and fear can be particularly acute if there is a threat of suicide. It has been estimated that up to 15 percent of people with schizophrenia commit suicide, and many more attempt it during their lifetime. Even when the course of the illness has stabilized, parents live with the constant fear that their child will not be able to take proper care of him or herself. Moreover, some people with schizophrenia become very angry and have difficulty controlling their feelings of rage. Some family members,

therefore, have to live with the fear that their child or sibling will attack them, if not physically, then verbally.

Siblings, meanwhile, have an additional anxiety with which to live. They fear that they may become schizophrenic themselves, especially if they are young and understand that there is a genetic component contributing to the cause of schizophrenia. (Epidemiological studies, however, indicate that the risk of a sibling developing schizophrenia is less than 10 percent.)

Anger

Prior to the establishment of a firm diagnosis of schizophrenia, it is not unusual for parents and siblings to be angry at their ill family member. The behavior of a schizophrenic may seem to indicate laziness or stubbornness or, worse, the complete abandonment of activities that are to be expected of a maturing individual. The person who is developing schizophrenia may drop out of school, no longer pay attention to grooming and be unable to get along with anyone.

Siblings often feel angry that so much attention has been directed toward their sick sibling. It may be that for many years their parents have been overwhelmingly preoccupied with the care of the sick child, often robbing the healthy siblings of the attention that would normally have been directed towards them.

Relatives may also become angry when their loved one refuses to take their medication, especially if it proved effective in the past. Understanding that this "denial of illness" and refusal to take medication is part of the illness

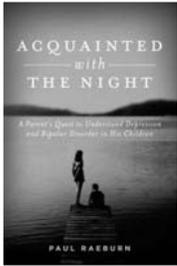
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THE KENNETH JOHNSON MEMORIAL RESEARCH LIBRARY

Book Review: *Acquainted with the Night*, by Paul Raeburn

by Alison Burke



In *Acquainted with the Night: A Parent's Quest to Understand Depression and Bipolar Disorder in His Children*, former *Business Week* editor Paul

Raeburn writes with withering and often self-deprecating honesty about the dual despair of his family's struggle with mental illness and the dissolution of his marriage to his wife, Liz. These two issues are interwoven to create a tragic memoir of one family's slow emotional collapse.

Following a violent outburst in class and years of subsequent behavioral problems, Raeburn's middle child Alex is diagnosed with bipolar disorder. Not long after, the author's youngest child, Alicia, begins showing signs of severe depression. By her early teens she is suicidal and consistently surrenders to urges of self-mutilation.

In trying to get his children the proper diagnoses, medication and hospital treatment they need, Raeburn spars with a wide range of adversaries, from one of Alex's teachers who merely considers him a "bad kid," to the insurance companies who provide minimal coverage, to the psychiatrists who offer the family few resources and little insight into the children's conditions.

Raeburn succeeds at illustrating the frustrating lack of cohesiveness in the mental health care system. His is a fist-shaking, but hopefully cathartic rebuke

against its ineffectual bureaucracy. It is hard to imagine, for example, that the metropolitan-area hospital that releases his son after treatment has no idea where to send him for outpatient care -- yet there are undoubtedly countless families throughout the country who could easily report on the same experience.

Still, some readers may bristle at his often erratic emotional responses to the children. He and his wife make no secret of their animosity towards each other, and they fight viciously in front of the kids. While he is prone to violent outbursts of anger, she often refuses to establish any boundaries for the children and appears apathetic in regard to maintaining their treatment. Together --as Raeburn admits throughout the book-- they are inconsistent disciplinarians who are unable to agree on what limits to set and thus sustain any semblance of order, stability or security for their children.

Since its publication in May of 2004, numerous reviews have already been written about the book. It is not surprising that many critics summarize the plight by saying that maybe if Raeburn and his wife simply exercised better parenting skills, the kids would be alright. If only it were so easy. Though it is certainly true --and again, Raeburn mentions this throughout the book-- that stability at home may nudge a child toward recovery and that living in the middle of an emotional tempest does exacerbate symptoms, mental illness (like any disorder) requires a series of approaches that includes ample and consistent treatment, sympathy from

loved ones and emotional support from the community. But as Raeburn points out, these are often in short supply for individuals and families struggling with biochemical illnesses.

All of which makes you wonder what the lack of community support can do to a family. Without social acceptance and understanding, parents may feel marginalized and be led to believe that they have failed to provide the proper tools of development for their children. And because mental illness is so misunderstood and stigmatized, there is plenty of room for blame. Raeburn himself perpetuates this game, as he searches fruitlessly for a fall guy on which to pin his frustrations.

For parents who have had to struggle with educators, health care officials and psychiatrists to get the treatment their child needs, *Acquainted* may hold no new insights. And it does not offer parents any words of hope or resolution. There is no pat conclusion in which he announces triumphantly that he and his family emerged from the "night" unscathed. His family is, like many others, thoroughly scarred by its experience.

Shortly after Alex is diagnosed with bipolar disorder, Raeburn meets author Kay Redfield Jamison, who wrote of her struggles with the illness in her memoir *An Unquiet Mind*. Raeburn asks her to sign a copy of her book, which she does. "To Alex: Things will get better." This, Raeburn feels, provides Alex with a glimmer of hope. But as any parent in the same situation knows, there sometimes is no happy ending, only the wish that the not-so-distant future may be filled with a little more light. ❖

JOIN OUR FREE BOOK and POETRY CLUBS: The **BOOK CLUB** meets at 6:00 pm on the **FOURTH MONDAY** of the month. The **POETRY CLUB** meets at 6:00 pm on the **THIRD TUESDAY** of the month. Meetings take place at the NAMI-NYC Metro office.

Library hours are Monday through Friday, 10:00 am to 5:30 pm. The Library is open to the public and all NAMI-NYC Metro members may borrow books. Please call 212.684.3365 before coming to make sure the Library is not reserved for a meeting.



2004 Annual Awards Celebration: *Planting Seeds of Hope*



Adele Anshien Volunteers of the Year award recipients Gordie Cooke and Nancy Parker



NAMI- NYC Metro Executive Director Evelyn Roberts



(l to r): NAMI- NYC Metro Board President Charlotte Moses Fischman, Carol Anshien and Dr. Kenneth Davis



Harriet Jaffe with former NAMI- NYC Metro President Michael Silverberg, Carol Anshien and guests

Dr. Anand Pandya and Dr. Howard Telson's family accepted the Posthumous Recognition for Special Achievement in Community Mental Health in Dr. Telson's memory



NAMI- NYC Metro staff members: Accountant Ping Maquiran and Director of Services Susan Saler



Special Achievement in the Field of Mental Health awardee Dr. Kenneth Davis and NARSAD President Constance Lieber

NAMI- NYC Metro Board members Julissa Viana-Hernandez (1st vice president) and Charlotte Moses Fischman (board president)



Presenter Hunter McQuiston, M.D.



Thank you to everyone who made this year's awards celebration such a wonderful success.



(l to r): Dr. Vansh Sharma presented the Department of Psychiatry at Mount Sinai Medical Center with the Special Achievement in Hospital Mental Health. Dr. Jack Gorman accepted the award on the center's behalf



NAMI- NYC Metro Board Member Karen Gormandy and James Knox



NAMI- NYC Metro Board Member Kelsey Batchelder, NAMI- NYS Executive Director David Seay and guest

NAMI- NYC Metro's silent auction featured donations from the American Museum of Natural History, Bloomingdales, Macy's and the New York Jets



NAMI- NYC Metro staff members and volunteers:
Front row (l to r): Anna Potluri, Lucee Martyn, Diane Lightbourne, Sabrina Esbitt, Jill Kurtzman, Elishka Canera
Back row: Dan Frey, Carlos Guitierrez, Roger Grayman, Mary Sheehan, Kenneth Randall



(l to r): NAMI- NYC Metro Executive Director Evelyn Roberts with NAMI- NYS Executive Director David Seay and Commissioner of the New York State Office of Mental Health Sharon Carpinello



MEMBERS' CORNER

A Consumer's Story of Success

by *Kenneth Randall*

In today's world, success can be measured in a number of ways. We often take stock of our professions, levels of education, annual income or material wealth and determine where we are in life. But for many mental health consumers, success is sometimes measured by achieving a number of goals that to others may seem unimportant or miniscule. While most people take for granted the routines and exigencies of daily life, such things for the "average" consumer may uncover untold challenges. Success, for many consumers then, is about hurdling obstacles both "large" and "small."

As a result of meeting a very accom-

plished consumer and professional in the field of medicine, I was compelled to ask her to share her own story of success. These are her words.

"It began with an eating disorder when I was 14 years old. I was hospitalized for six months. I thought the worst was over but I was wrong. After that I dropped out of high school and was hospitalized over and over again for the proverbial 'behavior problem.' I didn't know what this meant or why I acted so 'crazy.' Every day for me was a struggle. At any moment I could end up in a psychiatric emergency room or hospitalized. I was just a kid. I lost all hope. [But] I knew that I had a healthy side and that side made sure I got a GED and applied to college. At that time I was in intensive therapy with a private psychiatrist who saw me two or three times a week for years with-

out ever charging me.

Gradually, my mental health improved. I graduated college. A couple of years later I was accepted to medical school. However, I suffered a relapse of my disorder in my final year. While I graduated on time, I had to take off for treatment. And now I plan to begin my training in psychiatry next year.

Progress does not follow a straight line. Patience and perseverance are essential while struggling with mental illness." ❖

Join NAMI-NYC Metro as a volunteer. Please visit our website at www.naminyc.org or call the Helpline at 212.684.3264

NAMI-NYC Metro's Multicultural Workgroups Seek Collaboration, Outreach

by *Vanessa Levadas*

In October, NAMI-NYC Metro undertook an initiative to diversify its services by bringing mental health awareness, support and advocacy to a number of communities throughout New York City. Members, consumers, volunteers and staff contribute their time to three separate multicultural workgroups that reach the African-American community of Harlem, the Asian-American community of Jackson Heights, Queens and the Latino community of Washington Heights.

Each workgroup meets once a month to share ideas about how to better pro-

vide services, programs and outreach to these communities. In addition to fostering ideas to create future programs, each workgroup currently supports three existing partnerships to provide culturally competent services. The African-American workgroup seeks to support NAMI-NYC Metro and its collaboration with NAMI-Harlem to offer the 12-week Family-to-Family curriculum to families in Harlem. The workgroup is also developing plans for the upcoming African-American ½ day conference on African-Americans and mental health.

The Asian-American workgroup seeks to support the partnership between NAMI-NYC Metro and Hamilton Madison House to provide quarterly psychoeducation open houses to family members, consumers and providers in Jackson Heights. The open houses are conducted in English, Chinese and

Korean.

Meanwhile, our Latino workgroup supports the joint efforts made by Columbia Presbyterian Hospital's Parent Partners program and NAMI-NYC Metro. The Parent Partners-NAMI collaboration is a psychoeducation group consisting of a 9-week workshop, conducted in Spanish, for parents of children and adolescents who suffer from mental illness. The workshops meet once a week and are provided to parents of children and adolescents receiving services at Columbia Presbyterian's outpatient clinic.

NAMI-NYC Metro would like to extend an invitation to community members and leaders who are interested in volunteering their time to an important cause. Please call Vanessa Levadas at 212.684.3365 to join a group or to receive further information. ❖



Columbia Presbyterian Parent Partners Program

by Kathleen Durst

Fully two-thirds of children in need of mental health care do not receive necessary services. A significant contributing factor may be the lack of formal support for parents who have difficulty accessing and maintaining treatment for their child.

Parents in such a situation face multiple challenges: poverty, single caregiver status, mental health stigma, previous negative hospital experiences. Combine all this with a lack of adequate time, transportation, child care and other competing priorities, and parents may find it very difficult to comply with their children's treatment plans.

Moreover, within many child mental health clinics, parents are not properly educated about their child's disorder or the available treatment options, which further alienates them. Due to the overwhelming demands placed on pediatric mental health clinics, little time is given to understanding the family's background or their current needs, which may hinder treatment progress. One result is that hospitals lose significant

sums of money due to no-show rates of over 50%.

In response to these needs, the Parent Partners program was designed and implemented in February 2002 at the Department of Child Psychiatry at New York Presbyterian Hospital to assess the validity of improving a child's mental health treatment through parent education and outreach. What began as a research project was established as of November 2003 as an ongoing program in the hospital's Pediatric Psychiatry Clinic.

The program, consisting of intensive intervention to facilitate the parent's role, has four primary goals or hypotheses which were tested during the research phase:

- ♦ Ensure the child's weekly therapy attendance and medication compliance;
- ♦ Increase the parent's knowledge about their child's illness and refer them to additional community resources;
- ♦ Increase the parent's satisfaction with services in the clinic;
- ♦ Reduce the child's symptoms of psychopathology

The Parent Partners program works

towards these four primary goals by giving the parent an active role in improving their child's mental health. It encourages them to be a part of the process by understanding the diagnosis and treatment and working with the clinician on an ongoing basis.

Information is delivered in a sensitive, easy to understand and effective manner to ensure that the diagnosis and the type of treatment the child is receiving is fully understood. The core elements include the systematic engagement and education of the parents about their child's diagnosis and treatment plan, lessons in strategies and skills to use when they are navigating the many services in the community (hospitals, the Department of Education, Medicaid, unemployment, etc.) and ongoing support for them as they access these services for their children. In order to engage, educate and support large numbers of parents, we have developed weekly educational support groups that focus on issues identified by the parents as being vital to the mental health of their children and family. ❖

PROS and Psychoeducation

by James Reiser
and Virginia Trunkes, esq.

The state Office of Mental Health (OMH) is getting closer to implementing PROS in New York City. OMH defines PROS (Personalized Recovery Oriented Services) as "a comprehensive recovery-oriented program for individuals with severe and persistent mental illness." The stated goal of PROS is to integrate treatment, support and rehabilitation in a manner that facilitates the individual's recovery. To reach this goal, PROS will allow rehabilitation programs to benefit from participation in the federal Medicaid program.

OMH has included Family Psychoeducation (FPE) as one of the reimbursable tools providers can use

Take a course this spring

Family-to-Family

An opportunity for family members of individuals with major mental illness to learn skills to cope more effectively. This free 12-week course is taught by trained family members. Topics include medication, developing empathy for your family member's experience, self care and letting go of guilt.

Peer-to-Peer

This is a free 9-week course for people diagnosed with a mental illness interested in establishing and maintaining their wellness and recovery. The course, taught by trained mental health consumers, reviews aspects of mental illness and the mental health system including coping, medication, treatment and advocacy.

Contact the HELPLINE to sign up for the next Family-to-Family or Peer-to-Peer session. Classes fill up quickly. Call now to get your name on the waiting list!



to help facilitate an individual's recovery. FPE involves teaching family members, significant others or friends what they need to know about a loved one's mental illness and providing methods to work more effectively together to control symptoms and work toward a recovery.

FPE is considered an evidence-based practice that has been shown to reduce relapse rates. Research has shown that FPE is appropriate when clients are currently in contact with their family members, and surveys indicate that 84 percent of inpatients and 75 percent of outpatients have ongoing contact with their families. NAMI NYC-Metro offers one type of FPE in its Family-to-Family program and other similar support groups.

Providers who work with a PROS license will have the option to offer their own version of FPE. It is questionable, though, whether providers will feel they have any incentive to provide FPE. There are steps that both OMH and providers can and should take to ensure FPE is utilized to the fullest extent possible.

First, OMH can alter its reimbursement rate schedule. Among the various categories of monetary reimbursement, FPE falls under the Intensive Rehabilitation (IR) component, which also includes two other types of services. The current reimbursement rules specify that providers may only offer one of the three services in the IR component in order to receive reimbursement. Because FPE is a new service and the other two are very similar to practices that many current providers use, providers might ultimately disregard FPE. Therefore, OMH should reimburse providers at a higher rate for providing FPE than the other services. Under the current regulations, however, OMH will reimburse all three services at the same rate.

It is also imperative that the providers who do offer FPE are well-trained. Not all providers in New York are familiar with the FPE literature or implementation techniques. Research has shown that if providers are neither educated about the benefits of FPE nor offered guidance and support on implementation, it will fail. NAMI-NYC Metro has learned from pilot programs that getting families and consumers enrolled in FPE programs requires commitment and training among the program staff. New York providers need to learn how to do this, and it would be best if OMH led the instruction.

Further, if the Individualized Recovery Plan (IRP) does not include FPE, the provider should specify why that service is not included. To do so would ensure that providers are seriously considering the benefits of family involvement, particularly FPE for each PROS consumer. Despite the experiences of many NAMI-NYC Metro family members, the Health Insurance Portability and Accountability Act (HIPAA) need not be a barrier that prevents collaborations with involved families.

PROS has the capacity to assist in ensuring recovery for consumers in New York State and offers the best opportunity for the state's mental health service system to take advantage of FPE and foster widespread implementation of this powerful treatment tool. Structuring PROS in a fashion that encourages providers to vigorously implement the FPE component is critical. Hopefully, OMH sees the value of the familial role and will work to ensure its inclusion in consumers' IRPs. ❖

**Visit
NAMI-NYC Metro
on the web at
namincymetro.org**

Health Care Proxies May be Affected by HIPAA Ruling

by Jay Ukryn, esq.

The health care proxy has become a popular document, both in New York and nationally, for ensuring that a person has someone else to make appropriate health care decisions in the event that he or she is unable to do so. By executing a health care proxy, an individual appoints a trusted person as his "agent" and gives the agent the authority to make decisions if the individual is ever declared incompetent by reason of some mental or physical impairment. A health care proxy allows a patient and his or her loved ones to avoid an expensive, time-consuming guardianship proceeding while ensuring that the individual's wishes are carried out.

Nevertheless, while the concept of a health care proxy was gaining in popularity during the 1990s, laws were passed to protect patient confidentiality and restrict the disclosure of patient health information. The federal Health Insurance Portability and Accountability Act (HIPAA) was one such law. A recent New York court decision examined the apparent conflict between a health care agent's authority and a health care provider's obligation to ensure patient confidentiality, and ultimately clarified the document's powers.

In *Mougiannis v. North Shore-Long Island Jewish Health System*, a hospital patient's daughter had requested access to her mother's medical records after the hospital had declared the patient incompetent. The patient had appointed her daughter as her health care agent through a valid health care proxy. But while the hospital recognized the daughter's decision-making authority granted by the document, it nevertheless refused the daughter's request for access to her mother's records, claiming that a health care



proxy does not give the agent permission to review the subject patient's records.

The state Public Health Law provides that only a "qualified person" may access a patient's medical records. "Qualified person" is defined as either the patient, a guardian appointed under Article 81 of the Mental Hygiene Law, the parent or guardian of an infant or an attorney acting on behalf of the subject. Though not included in the definition of "qualified person," a health care agent is considered an exception under the statute and should be permitted access. In addition to the New York law, HIPAA provides that a patient must offer authorization for the release of his or her medical information. Both the state and federal laws make exceptions for when release of such information may cause some "substantial harm" to the patient, such that it outweighs the rights of the person requesting the information.

In the Mougianis case, the hospital disregarded the statute's provision for a health care agent, maintaining that a health care agent is not a "qualified person" under New York's Public Health Law and that the patient had not signed an authorization such that HIPAA would be satisfied. After the parties had litigated the issue, the court ruled that the execution of a health care proxy requires that an agent must have all information reasonably necessary to help him or her make informed decisions in place of the patient. Instead of ordering the records released, however, the court ordered the hospital to provide the agent a proper appeal of the hospital's denial in order to determine whether the release of the records fell under the exception of "substantial harm" provided in the statutes.

Although the ruling in this particular case was in favor of the health care agent acting on behalf of the incompetent patient, it would be wise for anyone preparing a health care proxy to include language in the document to satisfy

HIPAA, granting the health care provider permission to release any and all medical records under its control to the patient's health care agent. To be even safer, a HIPAA release form may be drafted separately to specifically grant the agent access to the records.

Breaking the Deadlock...

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providers participate in an educational and rehabilitative program in which they learn how to handle illness-related issues, develop social support, advocate for themselves or their loved ones and seek out case management.

The implementation of FPE produces a shift from a purely medical model to one of proactive collaboration. Participants have the opportunity to both learn and teach by taking on at various times the role of educator, student, advocate and mediator. No one person is positioned as therapist or expert. In this setting, the family moves from dysfunctional to competent, while professionals are seen not as practitioners but as agents working with families as collaborators. The goals are to empower the participants, not simply to treat the pathology.

It's important to realize that we have known how to implement FPE for three decades; in 1988 the New York State Office of Mental Health (NYSOMH) underwrote a \$5 million FPE program. As a practice it is already part of the guidelines for the NYSOMH and other leading professional organizations such as the American Psychiatric Association and the Joint Commission on the Accreditation of Health Care Organizations.

Moreover, in a February 2002 Psychiatric Services article, members of the NYSOMH stated: "It is important that consumer groups and their families generate a grassroots demand for evidence-based services," of which family psychoeducation has the highest scientific rating of all the non-pharmacological interventions.

"We all make mistakes --family and social workers included-- because mental illness is so unpredictable," says FPE pioneer, Ellen P. Lukens, Ph.D. "We need a team effort, and family psychoeducation is the bridge." ❖

Join our Media and Advocacy Group (MAG)

Interested in getting involved in advocacy efforts? MAG meets on the first Monday of the month (except on holidays) at the NAMI-NYC Metro office at 6:00 pm.

For more information,
e-mail Jim Reiser at
jreiser@fortunesociety.org.

Mental Health Update

Our cable program highlights the unique experiences and advocacy efforts of the mental health community. Tune in **every other Monday** at **3:30 pm** (Time Warner (56)/RCN (108) or at **8:30 pm** on Time Warner (57)/RCN (109). Upcoming dates: 2/28, 3/14. The channel number may vary depending on your cable plan. Check with your cable company if you have trouble finding the show.



Boot the SHU...continued from page 1

A8849 does not have a sponsor in the New York State Senate. If a sponsor is not found, the bill will die and this inhumane punishment will continue in the prison system.

As a family member and advocate, I cannot understand why our state senators do not step up and sponsor legislation that will stop one of the worst human rights violations in the country. Within the past few years, there have been many articles, studies and reports on how the inhumane solitary confinement of distressed and mentally ill state prisoners wrecks devastation on their conditions. In the October 31, 2004 issue of the *New York Times Magazine*, author Mary Beth Pfeiffer wrote about the short life and tragic death of 21-year old Jessica Lee Roger, an inmate at the Bedford Hills Correctional Facility who suffered from bipolar disorder. After nearly a year in the SHU, she took her own life by tying a bedsheet around her neck and stragling herself. And in the newspaper's December 13, 2004 issue, there were two editorials on the subject of the criminalization of the mentally ill.

Real people, unreal treatment

S.D. is a family member of mine. He entered the Department of Corrections in 1996 and has spent the bulk of the past nine years in the SHU. When he was first sent to prison, he was delusional and extremely paranoid. He did not receive treatment for his condition until his advocate reached out to Prisoners Legal Services, and he became part of a class action suit. In the meantime he was brought up on further charges, for which he was given an additional 1½- to 4-year sentence.

Finally, in December 2000, he was sent to the Central New York Psychiatric Hospital. He did well in

the hospital setting, and received counseling and medication for eight months until he was stabilized. The behavior that had gotten him into trouble in the past was gone and his symptoms were under control. It was obvious that he needed to remain in treatment to continue his recovery.

So where is S.D. today? He's in the SHU, where he will continue serving a 25-year sentence. It is the policy of the Department of Corrections and the state Office of Mental Health to send people back to the SHU after they are stabilized. In most cases, people who experience acute psychiatric disturbances while in disciplinary confinement are sent to the Central New York Psychiatric Hospital, only to be returned to the SHU to finish their punishment. S.D.'s mental illness was not taken into consideration at the time of his hearing nor was it given consideration in possibly reducing the length of his sentence. Eventually, S.D. will be released directly into the community after years in the SHU, without any treatment.

Nothing constructive comes from SHU punishment. It is, effectively, double punishment for people with psychiatric disorders. Between lack of treatment, malnutrition and social isolation, mentally ill prisoners deteriorate quickly. Moreover, the use of the SHU does not protect the well-being of correctional officers, and it endangers the public at large once these prisoners are released. It also costs the state more money than properly treating people to rehabilitate and ultimately gain their mental health.

What can you do? Call or write your elected and public officials and tell them to actively support Bill A8849. Tell Commissioner of the OMH Sharon Carpinello your concerns about this inhumane treatment. Support Rights for Incarcerated People with Psychiatric Disabilities (RIPDS) and Mental Health Against Solitary Confinement (MHASC). ❖

The Facts

-- Excerpted from the Correctional Association of New York's *Disciplinary Confinement in NYS Prisons*: www.correctionalassociation.org/SHU-fact.pdf.

New York leads the nation in use of disciplinary segregation. Compared to other prison systems in the country, NY has both the largest number of inmates and the greatest percentage of inmates in disciplinary segregation. *-The 2002 Corrections Yearbook*

Prisoners with mental illness are disproportionately represented in disciplinary segregation. 11% of NY's state prisoners are on the mental health caseload (approx. 7,500 individuals). *-Department of Correctional Services*

Nearly 1/3 of prisoners with mental illness in NYS' SHUs had prior psychiatric hospitalizations. Over ½ suffer from depression; 28% are diagnosed with either schizophrenia or bipolar disorder. *-Correctional Association survey of 162 prisoners with mental illness in SHU*

There is no limit to the length of time a prisoner can be sentenced to the SHU. Some inmates finish their sentences in disciplinary confinement and return straight to society. *-Correctional Association survey of 162 prisoners with mental illness in SHU*

The prison system's sole psychiatric hospital, Central New York Psychiatric Center (CNYPC), has space for only 200 inmate patients. It has not increased its capacity since it opened in 1980, although the prisoner population has tripled over that time. *-Department of Correctional Services*

If you have any questions or would like more information about advocacy groups, published reports and articles, call Leah Gitter at 212.431.7276.



Timothy's Law...continued
from page 1

advocates who called for the immediate passage of Timothy's Law, the pending New York State parity legislation. If passed, it would mandate that employer-sponsored health insurance provide substantially equal coverage for mental illness and chemical dependency as it does for all other conditions including asthma, diabetes and heart disease.

The rally was led by Timothy's Law Campaign Co-Chairs Tom O'Claire, Timothy's father, and Paige MacDonald, executive director of Families Together. Some of our New York City legislators spoke at the event, including Assemblyman Jim Brennan, a tireless parity advocate, and Senate Minority leader David Paterson, who observed that as far as parity was concerned, "other states are leaving us behind." Senator Paterson was referring to the fact that currently 33 states have some form of parity law on the books. New York State, a national leader on many fronts, does not have a parity law in place yet.

We need Timothy's Law because it's good for New Yorkers

Included among the other invited speakers were Alexandra Zimmerman and Susan Wheeler -- two women with different stories to tell but both with a strong desire to see parity legislation passed. Alexandra, dressed in a purple jacket and holding a bunch of balloons, had just completed a 122-mile walk from her home in Warwick, New York to the Capitol in Albany in support of Timothy's Law. She spoke passionately and explained to the large crowd why her journey was necessary and why the passage of Timothy's Law was important to all New Yorkers.

Six years ago, when Alexandra was in high school, one of her classmates, Robin Jane Desrats, completed suicide. While the girls did not know each other,

they did share a bond, as both suffered with mental illness. Later, Alexandra found out about Timothy O'Clair, the 12-year old boy with mental illness who completed suicide shortly before his 13th birthday. Alexandra walked for Robin and Timothy and for all New Yorkers and their loved ones who live with mental illness, for those who go into debt,



Alexandra Zimmerman with fellow Timothy's Law supporters in Albany forgo treatment or are forced to give up custody of their children because they cannot afford needed mental health services.

We need Timothy's Law because it's good for businesses

Susan Wheeler, a small business owner, also spoke in support of parity legislation. Susan is the owner of the Star Group, a Binghamton-based employment services firm. She spoke at the rally to announce the formation of a new organization, Small Businesses for Timothy's Law, and to let our legislators know that there is support for parity in the business community.

Some of our elected officials in Albany claim that small businesses are opposed to Timothy's Law. But

Susan pointed out that savvy business owners understand that untreated mental illness costs American businesses billions of dollars each year. Research shows that poor mental health management in the workplace, including inadequate mental health benefits, can hurt businesses through lost productivity, increased short-term disability costs and can lead to higher overall health care costs. Depression alone (the most prevalent mental illness among people in the workforce), costs businesses \$44 billion dollars annually, with an estimated 200 million days of missed work each year.



Star Group CEO Susan Wheeler said, "Opponents of Timothy's Law would have us believe that the costs associated with providing mental health parity to our employees is unaffordable," Susan said, but added, "a Price WaterhouseCoopers study estimates that the passage of Timothy's Law would only increase premiums for employers by only \$1.26 per employee per month." In terms of passing Timothy's Law, she concluded, "it's not a matter of if we can afford to, it's more a matter of how can we afford not to."

If you are a small business owner who is **interested in finding out more about Timothy's Law** or in joining the growing number of businesses who support parity, visit us at:

timothyslaw.org/sbftl.htm
or contact Wendy Brennan at 212.684.3365; email: WBrennan@naminc.org.

If you would like to help us with our efforts, please call to receive brochures to share with small businesses owners in your community.



Ask the Doctor...continued
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itself may help to lessen that anger.

Shame

Much has been done by family members and NAMI to counteract the stigma that is still associated with mental illness. Nevertheless, even when parents and siblings know that their ill relative's behavior is not under his or her control, feelings of shame may emerge. The ill may look awkward or strange, preoccupied or withdrawn from the world around them. They may not be responsive when spoken to, especially if they are hearing voices or are otherwise tuned in to their own delusional thought processes.

So what can we do to help?

First, every parent should become as knowledgeable as possible about the illness. There is no longer a reason why parents have to be passive and rely solely on the doctor's opinion and advice. There is so much information from local mental health agencies, on the web, in conferences and from NAMI groups that parents can become well informed about the illness and their medications.

Parents should try to maintain and communicate a hopeful attitude about their child's illness. Long-term follow-up studies of those with schizophrenia show that though the most devastating years are those from 20 to 30, there is often improvement starting in the 30's. After that, there is gradual improvement, particularly if the patient gets good treatment and family support.

Parents are often so devastated by watching this illness wreak havoc upon their child's life that they too often withdraw from social life. I encourage them to continue to do the things that gave them pleasure and meaning.

I also urge parents to be as open as they can with their friends and relatives about the fact that their child has a mental illness. The stigma of mental illness often prevents parents from being honest about their child's struggle. I believe that such feelings will change once it becomes widely accepted by the greater community that mental illness, like so much else, is biological in origin.

It is important for family members to encourage their ill loved ones to try as much as possible to live a normal life. Once their illness is relatively stable and medications are in place, the task becomes one of rehabilitation. Because stress can exacerbate symptoms, changes should be made slowly and carefully. We have seen that over time, despite the persistence of symptoms, people with chronic mental illness have the capacity to resume some of the important aspects of their life.

Today, psychotherapy is very useful in helping the patient learn to deal and cope with symptoms. It is extremely important that the patient have a long-standing, ongoing relationship with a psychiatrist he or she can trust, someone who will be reliable and offer constant support.

My own experiences, and those of many colleagues, have taught me that parents and siblings can make a difference. Psychiatrists and other mental health professionals are, of course, important contributors to the improvement that we see in patients. However, I know that the family members are of equal importance in achieving the kind of improvement in our loved ones that we so fervently hope for. ❖

--Excerpted from Dr. Willick's speech given at the 2004 Annual Conference of NAMI-New York State, October 29, 2004.

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SUPPORT GROUPS & EDUCATIONAL COURSES

Due to occasional changes, confirm dates and times on the day of the meeting by calling the Helpline at 212.684.3264.

educational courses

Family-to-Family Course

12-week crash course on mental illness that offers a comprehensive curriculum in a supportive environment. To sign up for the next session, call the Helpline.

Peer-to-Peer Course

9-week learning program for people with any serious mental illness interested in establishing and maintaining their wellness and recovery. To sign up, please call the Helpline.

groups for families and friends

Caregivers of children & teens

On Hiatus

Facilitated by a parent of a child with a mental illness, this group is for all parents and other caregivers of children and teens with a mental illness. Contact the Helpline for more information and to get on the waiting list.

Teen Sibling Group

On Hiatus

This group is for teens who have a sibling with a mental illness. Facilitated by an adult Janet with years of experience coping with a sibling with mental illness. Group is run at the same time as the caregiver group above. Contact the Helpline to get on the waiting list.

Criminal Justice

Leah Gitter & Kate Gandall

For family of mentally ill individuals in the criminal justice system and coping with legal, psychiatric and medical crises. Meetings are the 4th Thursday of the month at the NAMI office, 6 pm. Call Leah at 212.431.7276 with questions and to confirm meeting location each month.

Daughters and Sons

Stasia Pasela and Maggie Jarry

For adult children of mental health consumers. Group is held on the 2nd Monday of the month at the NAMI office, 6:15 pm. Contact The Helpline for more information and a facilitator will call you.

Family & Friends

Trudie Pass

For family & friends of persons with severe mental illness who need support & practical information. Meets the 2nd Wednesday of the month. Contact Trudie at 212.746.5731.

Family & Friends of

Individuals w/ Mood Disorders

Celeste Wallin

For any family member of a person with manic depression, depression, cyclothymia, dysthymia or schizoaffective disorder. Meetings are held the 3rd Tuesday & Wednesday of the month at 6:30 pm. Please attend only one meeting per month. Contact Celeste at 917.701.7239.

Family-to-Family Group

Patti Sacher

For those who have completed the Family-to-Family course, join Patti on the 1st Thursday of the month at the NAMI office, 6 pm. Call Patti at 516.466.8299 with questions.

Family & Friends of Individuals

w/OCD

Alicia Hirsh

For any family member or friend of a person with obsessive-compulsive disorder. The group meets the first Tuesday of the month at Mt. Sinai. Call Alicia at 917.941.5019 and leave your name and phone number. The facilitator will contact you.

Families of Children & Teens

Gordie Cooke & Nancy Parker

For parents and family members of children and teens with severe emotional/behavioral disorders or mental illnesses. Meetings are held the 2nd Monday of the month at the NAMI office, 6 pm. Contact Gordie at 718.402.3311 or Nancy at 212.787.5965 with questions.

Sibling & Adult Child

Sharon Bogart

With a focus on the "well" sibling or adult child, this group meets the 2nd Thursday of the month at the NAMI office at 6 pm. To attend, call the Helpline.

Uptown Family

Susan Hirsch

For all family members of a person with a severe mental illness. This group meets the 1st Thursday of the month at 6 pm. Call Susie at 718.857.0369 for details.

West Queens Family Support

Paula & Maria

Call Pauline at 718.441.6870 to attend this meeting for education and support of family members of individuals with a mental illness. Meetings are the 2nd Wednesday of the month.

consumer and family group

Bronx Norwood Family &

Consumer Group

Pam Silvestri

A place for families, friends and consumers to share their experiences & coping strategies. Meetings are held at 7 pm, every Monday at 277 Van Cortland Ave East, Apt 7J. Call Pam at 718.515.4823 with questions.

groups for consumers

Awakenings (Manhattan)

Dan Frey & Rick Sostchen

Support and sharing of strategies for successful living. Meetings are the 1st Tuesday and 3rd Monday of the month at the NAMI office, 6 pm. Call 212.491.1367 (Dan) or 718. 875. 7744 (Rick).

Awakenings (Brooklyn)

Rick Sostchen

Support and sharing of strategies for successful living. Meetings are every Wednesday at 250 Baltic Street, 5-6:30 pm. Call Rick with questions at 718.875.7744 (day) or email rsostchen@balticstreet.org.

Awakenings (Queens)

Edie Klein & Erica Abbensetts

Support and sharing of strategies for successful living. Meetings are the third Thursday of every month at 6:00 pm. Please contact the Helpline and the facilitator will call you.

Client Support Network

Mark Hollander & Doug Leeds

This group is for mental health consumers who wish to address social goals and learn about consumer resources in NYC. Meetings are the 2nd Friday of the month at the NAMI office, 6:30 pm. Interested parties should contact the Helpline for information and details before attending.

Individuals with OCD

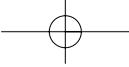
Lauren Priday

This group offers support and cognitive behavioral techniques for people with obsessive-compulsive disorder. Meetings are on the 1st Tuesday of the month at 5:30 pm at Mt. Sinai. Contact Lauren at 212.659.8871.

Job Talk

Ed O'Donnell

Professional guidance and peer support for consumers with employment-related concerns. Meets on the 3rd Friday of the month at the NAMI office, 6:45 pm. Call the Helpline with questions.



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If you have any questions about membership, please e-mail membership@naminyc.org.

