*In this issue; *Hospital planners go wrong *Kendra's Law doing well here *NAMI annual picnic plans *Men in YMCA building are adjusting *The problem about HIPAA *Reconsidering Fountain House *Getting kicked out of PROS*

NAMI-Schenectady E-NEWS

National Alliance on Mental Illness

August 1, 2014
Nat'l Alliance on Mental Illness of Schenectady

Darin Samaha, right, and Kevin Moran

Kendra's Law alive and well in Schenectady County

New York's Kendra's Law is at the heart of the controversy over the Murphy bill in Congress and its Democrat alternative, the Barber bill, co-authored by area representative Paul Tonko. Kendra's is the model for Assisted Outpatient Treatment laws (AOT) in other states and so takes center stage.
We believe Kendra's is one of the most important laws that families have to assure that someone who can't live safely in society will get priority attention from local treatment services to avoid further trouble. Without it, too often someone displaying aggression or violence in the home or on the street becomes more dangerous and this leads to the tragedies we've all read about.

Schenectady County has run this program for several years, back to its Kendra's Law beginnings, with at least a few cases each year, from what we hear. An AOT coordinator, Susan Aiken, in the Office of Community Services directs the program.
"At any time we usually have 12 court-ordered people in AOT and two who are receiving an enhanced service package," explained Darin Samaha, director of the office. "There are two components to AOT—one is to take people to court and set a traditional plan in place. Medication is prescribed, it might include stays in a residence and they have to have an assertive community treatment team or a care coordinator.
"There is a different, less formal version of the plan we developed where we can monitor them. It doesn't involve the court but requires agreement of all the parties to accept a treatment plan. That's the enhanced treatment package. It's part of AOT—a lot of other people do it. But over the years we've shifted more to court-ordered AOT. Everyone we've brought to court for AOT has accepted it. The relevance is that in some places they have a high denial rate. Treatment providers know they have a higher standard of monitoring with a court order. We have care coordinator meetings about this."

The NYS Legislature lined up behind bills to strengthen and

continued on page 4

Ellis' Golub Emergency Dep't., under construction

Where do the hospital planners go wrong?

(Rejoinder to an article by Monica Oss in Open Minds briefing July 24 titled "Are Hospitals Days Numbered?"and to a host of other writers who see the world of the traditional hospital fading away.)
All we seem to read are pieces about how hospitals aren't needed--they've become too costly to build and maintain, they're overcrowded, too slow and too labor intensive. The whole shift is toward outpatient and emergency facilities, scattered site, cheaper and quicker for patients to get to. No more construction of towers with their concentrations of expensive equipment for heart and cancer surgery. Instead the new lions push for expansion of high technology into lesser places close to the neighborhood. We're already seeing it here with Ellis, St.Peter's, Albany Med and the others opening Urgent Care Centers along the Northway. Even closer to home are planned office-like clinics slated to open soon in Glenville.

People who write about this act as if we don't need hospitals any longer, we can substitute clinics and urgent care centers for almost all that they do. It isn't so. We still have people who get severely sick, whether from physical or mental illness. We still trust the hospital to care for our very sick relatives who we bring silently to the emergency room with our hopes and prayers. We still need the hospital's specialized offerings--heart monitors and surgical interventions, radiation equipment, MRIs. And we need the hospital for some patients, like those who have grown too confused or depressed, to have time to rest and find a haven before they return to the outside world.

Monica Oss, a consultant who writes on business and health care for Open Minds, cites other writers who focus on the delivery of care away from core hospitals. One is Robert Pearl, MD, who sees a future with fewer hospitals but with increased volumes, as providing higher quality of care and better clinical outcomes. Another is Philip Betbeze, writing in HealthLeaders Media, May 30, who says that maybe in the future, hospitals won't be hospitals at all.

Betbeze writes: "Pursuing expensive inpatient volume in the traditional sense is a strategic dead end. Any new construction undertaken by hospitals and health systems should be based on

continued on page 3

Jumping Jacks picnic July 16 found about 30 of us lined up together at mealtime. At right, John G and wife Kristine share a smile while in food line.

Meetings and events

Picnics and more picnics

Night out at Jumping Jacks—Surprisingly, this little invitation we made to PROS-goers resulted in over 40 people signing up for a fast food supper that NAMI paid for the evening of July 16. It was concert night, too, over at Scotia's Freedom Park amphitheater next door to Jumping Jacks. The Audiostars, billed as party rock, were playing at 7. Thirty of us showed up, got in the food line together, and sat with one another in a square of tables. Great opportunity for all of us to get to know each other better. Lots of conversation. Some of us with cars drove the consumers home after supper while those who wanted to stay would be taken home later after the concert. The Audiostars rocked the place, really loud, and all kinds of singles and couples broke out dancing up in front of the stage. (Makes you tired to watch all that energy expended.) Among the folks there were quite a few from Mohawk Opportunities housing after Joe Gallagher heard our appeal for more transportation for those coming. Three more people came who attend the Franklin Street Clinic, plus two or three staff and several parents. This turned out to be good food and a comfortable night.

Supper in the park--Well, here's one that didn't work. We in NAMI set up a cookout supper in Central Park for Schenectady PEERs—the consumer group doing so much—on July 31. I thought it would go smooth as a hotdog roll but disappointingly, people failed to show. We cancelled just before 4 pm when we realized almost nobody was coming. Two of us met a consumer member of PEER over at the park but no one was in the assigned place. We had made preparations and brought the food. Now, the packages of hotdogs and hamburgs, the rolls and chips will be given to a church supper. Can't blame the weather after a doubtful forecast--it was sunny all pm. Just a bummer and so will dim our hopes for more suppers like this. The idea sprang from the Wednesday suppers in various parks that members of former consumer clubhouse Collage took part in regularly only four years ago. They were favorite outings and we were trying to restore a tradition. We had frisbee throwing, music and games in mind, just like they did. Can't help but think people missed a good time.

Annual summer fund raiser picnic—this is our annual blast in Central Park, scheduled for Thursday, September 4. We have the pavilion from 4 to 8 pm, will have music on the keyboard by Vic Furnari to sing and dance by. Games, prizes and speeches besides a barbeque chicken dinner cooked at the site and served hot by Pie in the Sky Caterers, Inc. of Albany, part of Rehabilitation Support Services. Invitations go out in the mail in the next few days. We charge $20 for the dinner ($8 for consumers) which includes soft drinks, ice tea, watermelon and a dessert tray. We'll play an assortment of games such as musical watermelon; water balloon toss, and watermelon seed spitting. Board games will be on hand like trivial pursuit and monopoly, boggle and scrabble. Prizes to be awarded for contest winners and raffle winners. Meet the politicians running for office this fall who like to drop in on us. Among those slated for prizes are those to be judged top singers and dancers in the contests we'll have.

We won't have a regular lunch meeting in August but will resume in Sept. with meetings planned then. Until then, stay tuned.

NAMI family members and a friend shown at the new YMCA residence. From left, Flora and Rob Ramonowski, Patti Costa, Jeanne Moloney,Roy J Neville and Luz.

Moving the men in at the YMCA's new residence building at 845 Broadway on June 28--Several of us volunteered to help with the moving and guide the 155 residents to their new apartments in the four story building. Everything was bright and shiny, smart and clean, a home well worth waiting for.

Relatives mental health support groups

Relatives mental health support groups continue to meet here over the summer. Kevin Moran at Ellis and Frank Greco at the Franklin St clinic are the counselors leading these groups. Kevin's group meets at 6 pm every Wed night in classroom B-3 inside Ellis Hospital. You can call him ahead on 243-4255 if you are new to the group. These are conversational groups providing free counseling to those attending. Each person gets a chance to tell about their situation living with someone or in close proximity to a relative with a serious mental illness. You don't need to live in Schenectady County or have had a family member hospitalized at Ellis to take part. Park in the parking garage, walk through the main floor corridor to elevators and go to 3rd floor. Turn left, off elevator and follow hall to classroom. See signs on the wall. Frank Greco is counselor for the program at CDPC clinic at 426 Franklin St. which meets as-needed on Monday nights, 5;30 to 7. Call ahead on 374-3403. Frank also runs a support group in Albany at CDPC on alternate Thursday nights. Call 447-9611 x-4512.

Consumer news: Consumers can check the website Schenectadypeer.com for latest activities of the PEER group (see info@schenectadypeer.com). The PEER group continues its live YouTube Google-plus hangouts on Sunday evenings at 7 where they discuss things mental health-related and community activities happening "live" on the internet. To join them—call Mike Abair on 694-6953. PEER advisory board meets first and third Fridays at 1 pm at Apostrophe Coffee in Proctors Arcade. Ellis mental health crisis line is 243-3300. Dual Recovery Anonymous support group meets Thursdays 5:30 to 6:30 at Conifer Park Outpatient at 600 Franklin St. Reach Out newsletter for July-August is out. Find a copy on www.reachout.com.or schenectadypeer.com.

Personal news-- Schenectady co-president Mary Neville

continued on page 5

Hospital days numbered? *from page 1*

adaptability, patient flow, and efficiency gains—not bed count. As it turns out, the hospital of the future doesn't look much like a hospital at all. Instead, it's a cohesive amalgamation of plenty of outpatient modalities that represent growth in healthcare. Inpatient care, increasingly, represents stagnation and shrinkage, in the business sense."

That's strange, last I heard hospitals were interested in making money. Ellis, St. Peters and Albany Med compete furiously over their heart surgery and cancer treatment centers. They like bigness. They duplicate what the others have regardless of need—it's a matter of dignity and self-preservation. I don't see them changing their business line, except by state edict. Medicaid is calling the shots for the way hospitals operate by forcing them to be more efficient.

But that's not the argument. These writers claim you don't need the expensive stuff, when it's essential because people will continue to get sick and disabled and need open heart surgery and amputations and specialized care against infections and mystery diseases. Ellis is constructing a $60 million enlargement of its emergency department. You can see the cranes out back. Is it out of touch?

"In the past, the sky was the limit, in terms of what organizations were willing to do to attract volume. That calculus has changed drastically." Betbeze quotes another manager who points to the Patient Protection and Affordable Care Act, which "has now got 7 million people engaged in healthcare insurance who didn't have that previously. The inrush of patients will be outpatient-based." Ninety-five percent of the hospital organizations Betbeze surveyed said most of the projects they are undertaking are predominantly ambulatory.

You wonder if these writers ever had someone in the family really sick. I've just had my wife suffer a mild stroke and be admitted to an intensive care bed in Ellis's Neurology Department. Once she was placed in a bed the nurses and others paraded in watching for vital signs on the wall monitors, particularly her heart rate and blood pressure and what the medicines were doing. Intensive care is a mass of machines with nurses constantly checking the numbers flashing on the screen. Nothing is left to chance. In two days she was moved to a regular bed. The parade of people to take blood samples, check temperature, blood pressure and the rest continued day and night. The nurses work on computer consoles much of the time. We appreciated all that attention. It must be terribly costly. But it's what we all expect when someone is in bad shape and the hospital is the only place to bring her around.

Two days later she was shunted over to Sunnyview for rehabilitation. Not much different--there are spare computers lining the halls and all kinds of modernistic electronic devices on the floor and in the exercise rooms. The physical therapists and schedule planners and nutritionists began with her right away. It's labor intensive and must be expensive. They plan three hours a day for her therapy to restore arm and leg function. Without it she'd be far more handicapped the rest of her life. With the intervention, we're hopeful she'll recover much of her strength. It's all we have to go on—the best our community can offer.

Our predicament is repeated over and over. The staggering costs are why the rush to keep people out, not in, defying conventional hospital logic to keep the patients flowing. A two-week stay at Ellis is believed to cost about $14,000, Sunnyview about the same. An emergency room visit costs at least $500. How can we sustain these costs?

continued on page 8

Looking over new apartment in YMCA residence

YMCA men getting used to new quarters

The men at the Schenectady YMCA residence have been living in their new facility at 845 Broadway for just over a month. It's an amazing transformation for most of them. They had tiny rooms before without cooking or toilets or showers. Without modern chairs and tables, platform beds, closets and large windows in each apartment. Without a big outdoors patio with soft chairs under umbrellas where they can smoke and chat well into the night. Without comfortable community rooms on two of the floors. They had none of these before in the old 13 State St. residence the YMCA had occupied since 1926.

What's it like for the 150 or so men who made the move Saturday June 28 to their present home, the remodeled former Mica Industries building on Broadway? I spoke to some of them and the manager, Ed Kowalczyk, about the changes. Ed said among advantages, we now have the outside patio and community rooms as well as the dining room. The men can't smoke in their rooms but can do so outside on the patio, which opens up social opportunities, he said.

George hailed me as someone he knew from before at the Y. George helped set up the computers that NAMI donated to the Y after receiving them from the GE Elfuns in October 2012. I asked how he liked the changes. He said the transition still goes on. Some of the men with mental illness lived at the Y for eight or 10 years, he pointed out, and they're used to staying isolated in their rooms.

George is a go-getter. He's taking a college degree course on the Internet from Kaplan University. He has his own computer in his apartment and drives his car to the supermarket for his food purchases. He can cook for himself in his apartment on the new stove. He's observed three or four men at the cubicles in the new computer room but he doesn't go in there.

The men have meal tickets which buy them three meals a day if they choose in the downstairs dining room. The facility employs the same cooks and kitchen crew as before. It's a good deal, Ed said. A hamburger is a dollar. Where can you get that? Yet some men just eat breakfast or one other meal in the dining room and prefer to eat in. It's the novelty of having their own stove to cook on, he thought. Others cook for themselves to save money.

"I like cooking chicken wings," said Owen, an older fellow with an oxygen cord below his nose, squatting outside on a low wall. He drives to Walmart for his food sometimes or takes the van. He's happy with his new surroundings, except for the weeds out front. They spent all this money, he says, and we see these weeds out there.Ed, the manager, said later the landscaping out front was unsuccesful with hydroseeding and has had to be redone.

Do they miss the venerable 13 State Street building? It was home

continued on page 4

Kendra's law works here *from page 1*

extend Kendra's Law in January 2013. New York City had been hit with a wave of violent events by deranged people including a knife attack on a police officer in the Bronx, and two episodes in which people were pushed under moving subway trains. The governor's SAFE Act extended Kendra's Law for two years, through 2017 and the period of mandatory outpatient treatment under Kendra's was extended from six months to one year. In addition, a psychiatric review is now required before a mentally ill inmate is released from prison. However, the bills to extend Kendra's have had detractors and it has not yet been made permanent.

With the nation feeling the impact of the massacres in Newtown, Conn.; Aurora, Colo.; and Tucson, Ariz., programs to do something are drawing more attention. The Murphy bill, HR 3717, called the Helping Families in Mental Illness Crisis Act—requires states receiving Mental Health Block Grants to have an Assisted Outpatient Treatment law and a "need for treatment" standard for civil commitment to a hospital.

AOT is aimed at a small group who have a history of rehospitalization that is associated with going off medications. It allows judges to order them into mandated and monitored treatment and order the mental health system to provide the care. This ensures the most seriously ill go to the head of the line. And once those people are in treatment, it lessens the chance of their doing more exasperating acts.

Studies show that AOT reduces homelessness, arrests, hospitalization and incarceration. It has the blessing of NAMI national and NAMI-NYS plus many other advocates but is opposed by radical consumers and their allies who object to forced treatment of any kind.

While Kendra's Law has been on the books in New York since 1999 not all the counties administer this law. The state forces counties to pay part of the bill. The program costs New York $32 million for the 2,000 to 2,500 people under court order each year. Another $125 million is spent on enhanced outpatient mental health treatment for others, The NY Times reported. Most of the costs go for intensive case monitoring.

The record is more spotty in other states for AOT even though most of them have some kind of involuntary commitment statute. Murphy's Law would provide funding assistance to those states where counties have had difficulties passing a sturdy version of the law. For instance, in California, Laura's Law passed the Legislature several years ago but hasn't been enforced in most counties. It just got approved by the San Francisco Board of Supervisors in July after years of delay. Currently the Murphy bill and its AOT provision languish in Congress as the House goes on vacation through August.

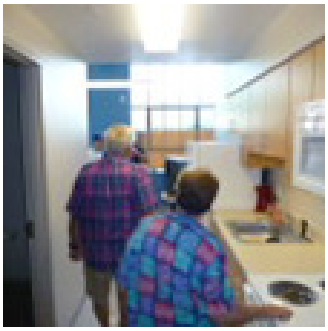
Back to Schenectady, someone not in compliance with a court order can be issued an AOT pickup order to put them in the hospital. An AOT pickup order doesn't require the "imminent danger" standard for involuntary or emergency pickup in the NYS Mental Hygiene Law, Darin said. .

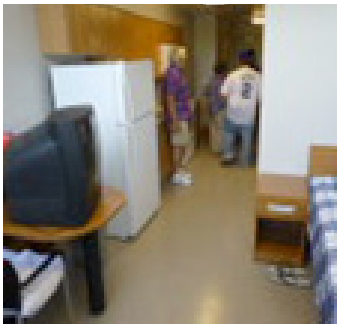
To explain this, under Kendra's Law one can be mandated to treatment if he's "unlikely to survive safely in the community without supervision, and has a history of lack of compliance with treatment for mental illness." By contrast, Section 9.39 of the law for emergency admissions and 9.37 for involuntary admission on certificate of a director of community services, call for pickup for care and treatment in a hospital of someone for whom there is "substantial risk of physical harm to himself…or a substantial risk of physical harm to others."

So for instance, if you didn't take your medicine for a few days we can have an AOT pickup, Darin noted. This provides us some leverage for someone to stay on a treatment plan. Let's say he decompensates and you can do a pickup order.

Darin, who was an AOT coordinator himself once, said our results with the two versions have been good. He once had a person who thanked him for putting him in the program and another who wanted to be kept on AOT even after it ended. His view is backed up by a recent NY Times report of a Duke University survey of people in NYS with severe mental illness who were ordered into assisted outpatient programs in 2004-05.

The study showed that patients were much less likely to end up back in psychiatric hospitals and were arrested less often. Use of outpatient treatment significantly increased, as did refills of medication. Costs to the mental health system and Medicaid of caring for these patients dropped by half or more, noted The Times





The way the studio apartments look at the new YMCA residence at 845 Broadway.

New home for men at YM *from page 3*

to about 180 men when it closed, many of them without another place to live. It got too beat up for us to restore, Ed said. If we could secure funding to renovate 13 State St. and staff it we could rent that building out. There is so much need in the county. It would be single room-only housing. The walls are so thick, it's a problem to rehab the building. It's now supposed to be in the hands of Galesi Construction and Metroplex, which hasn't let on what its plans are for the building yet.

The new building has about 155 single bed apartments on four floors. Most of the men who moved in have either a mental illness, drug addiction or physical disability. A small number do not, but would have been homeless and impoverished to qualify for a bed there, Ed said. The men receive Social Security or social services benefits to pay for rent and food and get medical care through Medicaid. Some go to treatment services downtown from one of the mental health clinics or the alcoholism clinic. A van takes them back and forth to appointments, or they are driven by others, or else they walk.

There is a small waiting list for a bed but little movement in or out since the building opened last month. Ed was asked if he would take someone who is discharged with a mental illness from Ellis Hospital who has nowhere else to go. He said he would speak to the discharge person there because sometimes a vacancy opens. "I know Kevin, I'll call him up," he says. The YMCA used to be a prime outlet for men coming from Ellis or Mohawk Opportunities, or the nursing homes. Now there are far fewer beds to offer but "We're still here to help," Ed noted.

HIPAA Privacy laws and the missing man

If you knew a young man with diagnosed mental illness was on the street homeless and vulnerable, how would you go about trying to find him?

We're thinking of the young man, Joshua Usher, who left a backpack outside the Target store building in Niskayuna on June 3, which led to the police calling the bomb squad, arresting the man and slapping him in jail for two weeks. He's 21, tall, dark haired and someone with a history of depression. You would have read about him in our July 1 NAMI newsletter. The case was dismissed by the judge in court June 18, after which the man stayed with an aunt two days, then disappeared into a street life. (Surprising, there was a repeat episode of the exposed backpack left outside the same Target store in mid-July, which stays a mystery.)

After he was freed, Joshua was seen on Facebook doing magic tricks for kids and supposedly trying to earn money from it. He has skills with magic tricks and he has held jobs in his past. Someone thinks he's gotten his job back, is all right. But no one knows for sure. Darin Samaha, the county director of the Schenectady Office of Community Services, said they're trying to engage him. Darin has been in touch but not recently.

On Joshua's last day in the county jail it was known that the fake bomb threat charges would be dismissed against him that night in Niskayuna town court and he would be directly released from jail. He thus wouldn't receive any follow-up by social workers at the mental health clinic, which is normal procedure for someone with a diagnosis of mental illness. However, we've learned that the district attorney's office and Darin directed that an Ellis social worker see Joshua in his cell that last day. She was to give him an appointment at the clinic, where he could be evaluated, prescribed medicine and referred to housing and other support services. It's believed he never went to the clinic. The social worker didn't reply to my question emailed to her and Darin says he can't answer that one because of privacy laws.

So the man remains a mystery. We fear he might meet harm while on the street, out of money and homeless. He is vulnerable though he has shown skills of self-preservation and has held jobs before.

In another case involving someone's privacy close to home, we know a young woman who survives on Social Security income and has received publicly sponsored mental health services in Schenectady until recently. She's a whiz at computers, has helped others solve their computer repair problems and lives by herself in an apartment in the city. About a month ago her friends noticed she appeared to be depressed and she told one of them she was feeling very bad. Then she dropped out of a favorite activity she did regularly with the group.

I couldn't reach her on the phone. Her close friend said he hasn't talked with her in a month. She has disconnected her phone and Internet service. She doesn't' come to meetings or anything. These are essentials for her. She's completely out of touch of her friends and she has no family here. This has gone on about four weeks.

Why can't we get in touch? Mostly, HIPAA—the federal Health Insurance Portability and Accountability Act. She's said to be no longer on Medicaid so she's not in either of the mental health clinic programs downtown. Instead, she has a private counselor, according to her friend, but he doesn't know her name. Even if we knew the counselor we wouldn't be given anything personal about the patient. Yet we fear she has gotten so sick she may need to be hospitalized or is already in the hospital. At least, she should have someone look in on her. No one can call.

These and many other cases of HIPAA secrecy in our lives plague families. It's time to loosen up the HIPAA rules to make them more reasonable when it comes to families' learning about someone's whereabouts or how to help in treatment. The Murphy bill in Congress (HR 3717, Rep. Tim Murphy of Pa.) would do this.

HIPAA and FERPA (relating to access to student health information at colleges and schools) require doctors to keep parents in the dark, absent a specific waiver by the mentally ill individual, writes DJ Jaffe of Mental illness Policy Organization. Neither James Holmes nor Jared Loughner, who were involved in shooting rampages, gave the waiver, hence their parents did not know school authorities identified them as needing help. Parents need the information about their mentally ill loved ones so they can ensure they have prescriptions filled, transportation to appointments, and stay in treatment. HR 3717 writes limited exclusions into the HIPAA law so family/caregivers get the same information paid caretakers would receive.

NAMI national issued a statement, Understanding What HIPAA Means for Mental Illness (April 18, 2014), to help clarify the law. It says the law is important because it protects confidential mental health treatment records. It also says, "Over the years, there have been many misunderstandings about the type and range of information that mental health treatment providers are allowed to share with others. This often resulted in situations where family and friends of a person living with mental illness were unable to communicate with healthcare providers, often to the detriment of a loved one."

Here are questions it answers: Can healthcare providers share mental health treatment information to family members and friends of a person living with mental illness? Ans.: Yes. If the person doesn't object.

Are health care providers required to obtain a signed informed consent release before sharing information with family and friends? Ans.: No. OCR's guidance states that providers may ask for permission to share relevant information, may tell the person they intend to discuss information and give him or her the chance to object, or they may infer the person does not object.

What happens if the person living with mental illness objects to information sharing? Ans.: If the person receiving treatment is an adult, objects to the release of information and is deemed capable of making healthcare decisions by the health care provider, then the provider may not share information with family or friends. Furthermore, the healthcare providers should disclose only the information that is directly related to the family member or friend's involvement in care.

Personal news *from page 2*

is in Sunnyview Rehabilitation Hospital after suffering a mild stroke affecting her right side July 15. She is receiving daily exercise, may be there till mid-August. Doctors say there is good chance of recovering lost function.... Jeanne Derwin Butler writes July 13 that her oncologist called to say he is sending her back to her transplant doctor for reconsideration. Jeanne says her updates read like watching a Wimbledon tourney where the fans get stiff necks from the back-and-forth...Mark Zawilinski, whose father and mother, Len and Bunny Zawilinski were long time members of NAMI, died July 7. Mark was 53, a resident of the YMCA for some time.....Cliff Mango, 59 of Schenectady, died July 11 at his residence as a result of various medical problems, according to his obituary in the Gazette. Cliff worked as a peer counselor at Ellis Hospital. He is survived by his wife, Nancy, daughter Maranda, two brothers, a sister and other relatives.....Holly Clark, long time manager of the former Collage clubhouse and more recently a social worker on the staff at PROS, has retired. Holly says she's finally recovered from a aerious back operation.

NYC's Fountain House an impeccable 66 years

(Much-shortened article in The Chronicle of Philanthropy, forwarded by Briana Gilmore of NYAPRS, July 17, about NYC's Fountain House consumer clubhouse, now in its 66th year. She writes:"We are working closely with Fountain House and other NYC clubhouses to ensure that this model of community-based rehabilitation is recognized and valued fully."
(Note to Briana: You need not look any further than Albany or Schenectady where the state killed the clubhouses three years ago, places we found also valuable. Fountain House stands above the rest, better than the government's PROS designs. They share the same goals as Fountain House—to create consumer self-sufficiency--but they don't send members to college, assure them of jobs, find them housing or use their own members to educate the others, as Fountain House does.)
The biggest danger for people with severe mental illnesses is not navigating the health-care system or finding a good therapist, says Kenneth Dudek, president of Fountain House, a New York charity that helps such people live independently—it's isolation. "What's happening to people now is they end up not spending time in hospitals anymore," he says. "Instead, what happens is they end up living alone. That in turn makes the illness worse, and people don't get the help they need."
For its efforts to provide a sense of community to its members, Fountain House and its sister organization, Clubhouse Int'l, have won the Conrad Hilton Humanitarian Prize.Six patients and two volunteers founded Fountain House in 1944 at Rockland State Hospital, in Orangeburg, N.Y. After their release, they met on the steps of the NY Public Library to give each other support. In 1948, the group became Fountain House. The charity has since expanded into a global presence, with the creation 20 years ago of a spin-off group, Clubhouse International. The organizations have established local clubhouses all over the world to serve mentally ill people. They work alongside professional staff to create and run programs that help people like themselves go to college and find jobs and permanent housing.
Holding members responsible for helping run each clubhouse is meant to be therapeutic,Dudek says. The practice lies at the heart of everything the organizations do. "We purposefully understaff our program so we rely upon the work of the membership, and that's part of the member's recovery process."
On an annual budget of $17-million, Fountain House serves 1,300 New Yorkers a year who are referred there by doctors, hospitals, and health centers. The organization's goal is to ensure every member can become self-sufficient. Fountain House helps members finish their education, whether it's a GED or completing graduate school. It also helps members find housing that offers them counseling and other services and gives them help in managing their medications and budgeting.
Its drive to make members self-sufficient includes a strong emphasis on employment. Through Fountain House's transitional employment program, local employers provide members with paid, part-time positions for up to nine months. The employers include major companies like Dow Jones, Estee *Lauder, HBO, and Pfizer.*

City Hall hearing June 9 on proposed casino drew large numbers pro and con.

Casino gambling bad for those easily addicted

(Letter to the editor, Daily Gazette, shortened and slightly altered, June 8):
For some of us concerned about the effect of casino gambling on people who become easy victims of compulsive gambling, the promoter's plan to bring a big gaming casino here or anywhere else in the state is a bad idea.
While a lot of people gamble socially and occasionally, others can't control their impulse to imagine themselves winners at the table or slots, at the lottery window, the video game terminals or in the next betting pool. They can't get over "the chase"—the drive to get back what they lost last time out. It's just like a heavy dose of alcohol or street drugs--the same addictive behavior is at work. The gambling urge can become truly destructive when it creates family breakups, loses someone a job, or even leads to suicide. Pathological gambling is now a separate addictive illness, apart from manic depressive episodes, which used to define it in the bible of the psychiatric trade, the Diagnostic and Statistical Manual of Mental Disorders (now DSM-5). The latest studies show that getting a monetary reward from a gambling type experience "produces brain activation very similar to that observed in a cocaine addict receiving an infusion of cocaine."
The symptoms for the compulsive gambler are the same as for drug takers: they experience tolerance (a need for larger or more frequent wagers to experience the same "rush"); withdrawal (restlessness or irritability associated with attempts to cease or reduce gambling); chasing (trying to win back gambling losses with more gambling); and lying (trying to hide the extent of his or her gambling by lying to family, friends or therapists).
Roy Neville

Demonstrators against the casino at June 9 hearing.

What do you do when you get kicked out of PROS?

Mike and Dinah were chatting on You Tube in their live video conversation Sunday night July 27 with guest Peter Hyson who told them about his being flat-out dropped from the Ellis PROS program. PROS is a rehab program for mental health and dually diagnosed consumers located next to the Ellis mental health clinic downtown at 216 Lafayette St. About 150 people in various amounts of recovery attend there, some daily, some one or two days a week. It's the state's way of sticking them in classes (groups) to build skills and learning, self-reliance, and to help them with jobs and recovery, as Medicaid approved therapy.

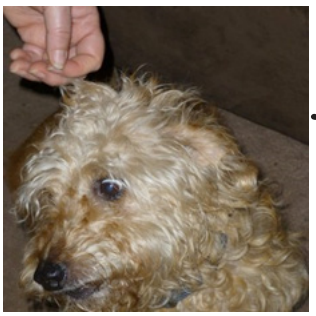
Peter is a healthy looking guy about 50 who was going to PROS groups five days a week plus seeing a doctor and counselor there. He also said he held a job at the same time or before. Then he got the bombshell of a phone call.
That came a month ago from his counselor, Dutch, who wanted to meet with him to tell him they were dropping him from the program. The explanation was that he is doing too well and the clinicians held a meeting and decided the program had done what it could for him. "I still have times when I get sick," Peter says. He has nowhere else to go, has to find a new counselor and doctor, and is at a loss to know what to do with his time.

The Sunday conversation is for all to hear—it's called a video hangout and this was number 60 so anyone can see it on the consumers' website schenectadypeer.com or You Tube. So here goes: Peter says he got a call from Dutch to come in and speak to him a month ago—they were kicking him out (discharging him). He had 30 days to find referrals to a doctor and any other services he needs.
He's attended PROS for two years and before that the continuing treatment program for many years. That's where all the people he knows come from. He had a doctor and counselor but that would suddenly halt. It was so sudden Peter says he felt rejected. He appealed to others but a staffer told him: You're doing good and you're working and it's time to move on. Peter says: "I've been out of the hospital for six years. It's hard to leave when you know people for years--they're your support."

He was given a reference to counseling services on Upper Union Street. Mike asks "Is that the old house with the pillars in front that was owned by the guy who was doing kinky things in the basement? It might be, they said. When Peter went there they told him he was overqualified and he couldn't get in. Peter says: "I have addiction and a mental illness and I'm overqualified? I got back on the bus and laughed all the way home."

"You don't have Medicaid?" says one. "No, he has Medicare," says Mike. "It's a billing issue—the almighty dollar." Dinah says: You're being punished for doing well. There should be something for mental health people as a way to appeal. You should go to your doctor and say to him how you feel. It's not easy to change doctors. And Mike says: Why can't they switch you to another doctor at the clinic? It raises the question how much impact we have into our own treatment. It comes down to money and your case loads.
On making an appeal, Mike said it might not work because PROS tells you when you come in you're going to be discharged at some point. But you're not getting much time to process this—why can't they make it gradual? It's going to be a big change, you're going to have to find something to do. You can come to the SchenectadyPEER meetings, every first and third Friday. We're planning a whale watch and maybe another Lemon Ball. Dinah agreed it was a big change, far too sudden. When push comes to shove it's not our decision, she says. You might not be able to appeal but you could become set back—you could have a relapse because of it.

continued next column



Happy ending for Nemo and evicted mom and son

(Story comes from an appeal in an email July 2 sent by Judy Zuchero, director of the Office of Disability Services in Schenectady City Hall, to her staff and friends.)

Dear Staff: I have a very sad situation with a disabled senior and her disabled son who is about 40. Long story, but they were evicted (apt. complex not nice at all). They are devastated by the eviction and now are being housed by DSS in a motel.

This is anxiety producing enough, but on top of it….they took their beloved dog "Nemo" to their vet to be boarded (which they cannot afford on their disability incomes) and the vet told them they have to come and get him because with July 4th coming up, the vet needs all the room he has to board dogs he committed to.

Sooooo….can anyone help foster this dog or know someone who can??? Nemo is: a 10 year old neutered male, has all his shots, is a terrier/spaniel mix, o.k. with dogs, cats, kids. She said the vet's office said he is very depressed…no kidding…M. and her son are frantic. I am on vacation next week, and I will leave M. and her son in Melissa's capable hands while I am out to help them with a housing search but any ideas/help for Nemo would be greatly appreciated! Of course, housing search will be challenging because of the pooch…they are going to look at a place tomorrow. If you have any ideas, call or e-mail me. Thanks soooo much!!!! Regards, Judy

(then on July 3, Judy writes) Hello all. I have an update and good news! Thanks to Nathan. Thank you so much, Nate!--he has found an "angel" who will take the dog for one month. I am hopeful that my consumer will find an apt. in that time. Thank you all for your kind attention and care!

Almost three weeks later, Judy writes: Yes, M. has found a place and they will take the dog! DSS assisted with housing at the motel and may provide one month's rent and help with the cost of movers. So a happy ending and God Bless our "animal angel," Karen Laing. Thanks to her, Nemo found safe and loving temporary housing!

(Editor's note: Judy said it's not unusual for poor families to be forced to give up their pet dog when they're evicted or lose their apartment. Landlords can refuse to take in a dog. The heartbreak is that the dog is often a beloved member of the family who they can't stand to part with even if it means more hardship looking for a place for themselves.)

Hospitals days numbered *from page 3*

But people eventually need to go to a full-service hospital and the flow of patients, especially with all the older ones, is expected to grow, not stay even. So hospitals aren't going to stagnate and shrink. The writers have it wrong.

We like hospitals to be close and convenient. We don't want them to close down or go bankrupt. There's no substitute for what a hospital does and we wouldn't want anything less for anyone else than the care my wife has received.

Emergency rooms bad for someone in psychiatric crisis

By way of argument, here's a piece that appeared as a Boston Globe Op-Ed, Nov. 7, 2007:"Hospital emergency departments are among the least appropriate and most expensive places for patients in psychiatric crisis. Yet these departments are where police, families, group homes, nursing homes, and others routinely take people who are agitated, panicked, or threatening to hurt themselves.

Emergency departments are also where people go at the end of the month when their medications run out, when their primary physicians can't see them for two weeks, when they are frightened or desperate and have nowhere to turn after 5 pm and their therapist's answering machine tells them to go to the ER. "Emergency departments and these patients in crises are both victims of a health care system that increasingly relies on emergency care to cover gaps in basic mental health and social services. Once at the emergency department, psychiatric patients wait twice as long for help as other patients, often in escalating frustration. Their interactions with harried staff, who often have little mental-health training and resent the long-term occupation of emergency beds, can make matters worse. Emergency departments don't have much time to provide reassurance, and often resort to restraint and seclusion—sometimes even handcuffs and pepper spray. Many psychiatric patients recount harrowing and traumatic experiences.

As the Globe reported this summer, psychiatric patients sometimes die and have bones broken in emergency departments. They are often stripped of clothing and left for hours. This has to stop for all our sakes: the emergency departments, people with psychiatric disabilities, and taxpayers who pick up the tab."

Editor's note: you are invited to call the editor, submit an article or letter about anything germane to local mental health services or the situations families and consumers face in our community, to run in the E-News. This is the monthly NAMI Schcnectady newsletter and is primarily issued via e-mail. if you want an e-mail copy send your e-mail address to the editor, rneville@nycap.rr.com. Back issues are on the website, namischenectady.org and can be downloaded in pdf format.

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