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NAMI Schenectady E-News for April 2015

Folks: This is our April 2015 monthly newsletter sent to members and friends of NAMI Schenectady, reporting on meetings and events and other items of interest. Your comments and questions are welcome. Reply to Roy Neville, editor, at namischenectady@gmail.com.

Next NAMI Schenectady chapter meeting is at noon on Friday, April 17 at the Van Dyck Restaurant, 237 Union St., Schenectady. Laura Bachelidor, director of the county's Office of Aged and Long Term Care, will be our guest speaker. Laura will tell about the mental health issues for the older population in Schenectady and the services available through public and private sources. We're concerned about the lack of housing, day care centers and meal sites as well as in-home services for seniors, particularly those with serious mental illnesses. There's a trend to move people out of nursing homes into community care beds and we'd like to know how this is going in our county.

Older people with either a chronic mental illness like schizophrenia or depression, or those with dementia or Alzheimer's Disease often have overlapping physical problems, too. They can be passed over in the mental health housing and community center social programs usually serving younger adults. There are very few local mental health group homes earmarked for the elderly. Older people have special needs that do not always fit them into the other programs. It's up to government and health care providers to see that those with special needs are accommodated. We want older people with these mental illnesses and conditions to have decent places to live and opportunities for social gathering with friends and companions. There aren't enough of these places for them to go now.

Our lunch on April 17 is in the dining room to the right as you enter the Van Dyck. We arrive 15 to 30 minutes ahead so that we can mingle. A buffet lunch at noon consists of sandwiches, salads, coffee and tea and is \$15 including tax and tip. We pay our treasurer, Cindy Seacord, at the lunch. You can reserve by telling us you're coming (call Roy Neville, 377-2619). But if you forget, come anyway—there are always more than enough lunches for all. We welcome friends and supporters of NAMI to join our group. And it's an excellent lunch. Find parking in the lot at the corner of Union St and Erie Blvd, a short walk from the Van Dyck.

Kevin Moran's relatives support and education group meets every Wed night at 6 pm in classroom B-3 of Ellis Hospital. Call Kevin ahead (243-4255) if you are new to the group. These conversational sessions are a way to have a more intimate understanding of the problems and situations that families have in coping with mental illness. So, if you are one of us, please consider going to Kevin's support group (not for the person who is ill). You don't need to live in Schenectady County or to have had a relative spend time in Ellis Psychiatry. Quickest way up is to park in the Oncology lot on Rosa Rd. (Lot 1), take elevator to third floor and find classroom down the hall. We think Kevin's group has proven to be a big help to many families. Occasional speakers are invited and films are shown.

Frank Greco's family support group meets Thursday evenings 5:30 to 7 in the family resource room at the Capital District Psychiatric Center in Albany. Call Frank on 447-9611 ext-4512. Park in hospital garage. Speakers scheduled: Thurs, April 6: Karen Laing, Health Literacy for All, How family members can reduce stress. Frank will also meet parents as-needed at CDPC Franklin St Clinic, Schenectady late afternoons. Call office, 374-3403 for appointment.

News of our NAMI crowd

Our chapter has a new pamphlet out, describing our activities and telling when and where we meet, prepared by Cindy Seacord. It's being circulated at our meetings and to clinics, libraries, housing programs, agencies and government offices....Cindy plans to hold a second "open house" or soiree at her home soon. We're to send out invitations in April. The small social gatherings are to bring together "newbies" at the relatives support group with older members so we get to know one another better and encourage more participation in NAMI activities....We're looking to sponsor a Family to Family class, one of NAMI NYS's training programs, but two of us need special training to lead this and the dates haven't worked. The 12-weeks class is a thorough grounding for families about the nature of mental illnesses, medicines and other approaches in treatment, housing and community services, state and federal funding, advocacy and political issues....We hope to have Jason Praden come here to speak. He's a recovered person who is an inspirational speaker for NAMI

audiences with a message about recovery...Our NAMI member Mame Lyttle is home now after knee operation at Ellis; you can call her on 438-9785 or send email to mlyttle@nycap.rr.com...Edie and Walter Morlock will be back April 8 from a vacation in Florida where we all would like to have been the past two months... In the aftermath of the Jay Street fire, NAMI Schenectady donated cash to four agencies helping to relocate fire victims and replace lost possessions. We gave funds to City Mission, Salvation Army, Bethesda House and Home Furnishings so they could buy mattresses and bedding, clothing, kitchen equipment and other necessities.

Consumer group activities

Schenectady Peers, a group of active consumers who have shared experiences in their video hangouts on YouTube, have a website info@schenectadypeers.com. Suggest you contact Mike Abair, 937-4262 (abair01@gmail.com)...Christine Jasikoff (580-1064) says consumer-led DBSA programs (Depression Bipolar Support Alliance) have closed in Clifton Park and Saratoga Springs. Our local DBSA support program closed previously. For contact, try the last trainer, Kathryn Tomaino, 346-8817.

Computers--Mike Abair said he will be teaching a class in basic computer and how to use Facebook at PROS for consumers who go there. Mike used to teach computer skills at the former Ellis Collage social club before it closed more than three years ago. Mike also said the cafeteria at PROS is now equipped for wi-fi that allows people to bring in their laptops and access the Internet, something they couldn't do before because the signal was too weak. Boosting the signal can make it far easier for the others to join in his class, using their own laptops....***Plans to open a consumer social club*** are still alive but waiting for outcome of fund raising efforts, according to Howie Vinick. Howie, who announced in January he hoped to open a consumer drop-in club to replace Ellis Hospital's Collage, said he's exploring various opportunities for sources of funds and is asking people to be patient.

Puzzles Bakery & Café, about to open April 2 at 515 State St., Schenectady has an inclusionary hiring policy that has led it to hire 18 part timers with autism and other developmental disabilities for its workforce. Owner Sara Mae Hickey, orienting the new hires, said she understood the problems for this group as she has a sister with autism. Some of those applying said they had been unable to find a job before. Some came with a job coach or parent to the interview. With more children and adults now diagnosed with autism, parents have become vocal advocates for jobs and housing opportunities for them.

NAMI lunch meeting March 27

Our speaker--The lowdown on dementia and Alzheimer's Disease

Neuropsychologist Mark Rogerson, guest speaker at our NAMI lunch March 27, explained how changes in the brain affect people's behavior, particularly the elderly with dementia and Alzheimer's disease. Mark, who has a private practice in Niskayuna, told what neuropsychologists do—evaluating patients through interviews, use of clinical psychology and tests of cognition and personality to create a picture of an individual's brain functioning. He said most of his patients are referrals from physicians.

Focusing on the elderly, he discussed how the brain changes with age. Mark said "some mild declines are normal, especially with processing speed, complex attention, and mental flexibility. Memory is not quite as good as when the person is younger, but impairment is not normal." Not all old people need get dementia or Alzheimer's, he pointed out, although the likelihood of encountering both of these increases with age.

Some warning signs consist of rapidly forgetting, even with cues; problems with language; confusion or disorientation; difficulty with comprehension, reasoning and judgment; and changes in behavior and personality.

He described dementias as a general term, not a specific diagnosis, arising from a variety of causes. There are several types, depending on what part of the brain is affected. For example, frontal-temporal lobe dementia causes problems with executive functioning such as planning, organizing, problem solving, initiation and flexibility in thinking. Someone might also show behavioral changes such as impulsiveness, socially inappropriate behavior or become apathetic. Lewy Body dementia affects Lewy bodies in brain cells. Parkinson's disease is laid to a loss of dopamine cells in the brain and features noticeable slowness, rigidity, tremor and problems walking.

Alzheimer's disease can cause dementia, he noted. More than half of dementia cases are those with Alzheimer's. Risk increases with age. Characteristic features are amyloid plaques and neurofibrillary tangles plus shrinkage of the brain

cortex. One's primary deficit is in lacking memory for new information and progressive difficulties are noted with language, executive functioning and behavior.

Mark also described symptoms of schizophrenia and bipolar disorder, occurring in both young and older patients. He suggested that a neuropsychological exam might be useful when there is any concern about a person's cognitive functioning. It consists of a review of the records, an interview and observations, test results and feedback to the patient. Mark thought it was important to help the patient learn as much as possible by having an accurate diagnosis and making the right choices about treatments. We thought it was a welcome approach to provide alternatives to the pill prescribing that usually accompanies these diseases.

The news: Fire downtown threatens vulnerable people in old buildings

They've taken the buildings down. Part of one wall was all that remained March 24 of the two tall buildings on Jay Street devastated by fire. Huge piles of rubble lay in the street in front of City Hall--bricks and masonry, jagged and charred timbers and twisted metal. These would soon be gone--a mess to clear up and cart away so we can try to forget that four people died and about 60 residents were displaced in that terrible late night blaze. We shouldn't forget. Those buildings were unsafe for the people living there—mostly poor people, some with mental and physical disabilities and some of them elderly. They don't deserve to live in housing in this city without proper safeguards in place—more protection than existed in those fateful buildings.

Dangerous conditions--The Gazette reported that residents who escaped the fire told about conditions existing in 104 Jay St.: No sprinkler system, fire alarms working irregularly, a couch blocked the fire escape, debris lay in the halls, cables ran down the halls for space heaters in the rooms. In short, a carelessly maintained property right in the shadow of City Hall and under the nose of city code enforcement. Unbelievably, inspectors were in the building the day before the fire. They reported that certificates for the boiler, furnace and some other equipment had expired. But what about all the other things not within code? Every landlord in the city knows how exacting city and Municipal Housing Authority inspectors can be, rummaging through an apartment. They check over doors and windows for proper opening and closing; operation of furnaces and radiators, leaking faucets and improper drains, missing lighting, poor electrical hookups and ungrounded wall receptacles, faulty smoke alarms and lack of a carbon monoxide detector, among other things. One inspector faulted me for cobwebs in the cellar and water on the cellar floor after a heavy rain. I whisked the cobwebs away. They don't allow you to move a tenant in till all violations are removed.

There's more to it than that. If landlords won't do it, the city and MHA should see that apartment dwellers in these old buildings get periodic training in how to exit the building in a fire, how to use a fire extinguisher, how not to overstress wiring circuits, and how to use the stove and heating equipment. That's the way it is for people in group homes for the mentally ill. There's a strict monitoring for conditions in these homes they would never let down on. But a private landlord in a deteriorating building with some of the same people living there can get away with even basic code violations. Such laxity puts our adult children with mental illness, scattered about the city in the only housing that will take them, at severe risk of fire danger.

Fires are not so rare in Schenectady for people with disabilities living in low rent housing. One of our members has two daughters who receive mental health services here. Both have been forced out in frightening fires in their apartments and they moved out because of this. In one case a man threw some kind of accelerant into the open door of the apartment across the hall which then went on fire. In another instance, a fire struck inside a multi-story apartment building downtown about the same time as the Jay Street blaze. It killed a man who lived on the third floor of Summit Towers, where there are many elderly and other people with mental or physical disabilities living in the building. Everyone on third floor was evacuated for three hours in the middle of the night. One of our friends on another floor who has a physical handicap and uses a wheelchair was spared having to flee the building in what must have been considerable turmoil that night.

Living in the poorer sections and attending group programs with other persons with these chronic illnesses or addictions also puts our adult children at risk of meeting up with dangerous characters. Gazette stories in March covered the jury trial of a man who was convicted and sentenced for the murder of a mentally ill man in his apartment on Wendell Avenue almost five years ago. We never reached the family to share our sympathies. Yet many of our sons and daughters have the

same lifestyle as the deceased man. They walk the streets, ride the buses and attend the same counseling and activity programs to serve the mentally ill as the man who lost his life.

Advocacy in the state legislature--NAMI NYS's main budget priorities (from NAMI NYS action alerts)

Reinvestment in Community services—We urge support for full reinvestment of savings from the governor's budget proposal to close 136 more beds in state psych hospitals, saving \$15 million. Community support services to receive these savings would ensure safe and affordable housing, case management, transportation, access to inpatient and outpatient treatment, vocational training and easier access to emergency facilities.

Expand police training by adding funds for crisis intervention teams. Ban solitary confinement for mentally ill prisoners

Raise the age of bearing adult responsibility under the law for committing a crime from age 16 to age 18

Incorporate mental health education in schools—pass legislation that would formally introduce mental health education to the health education curriculum. This would significantly raise awareness of mental health issues for students.

Prescriber prevails—this is the provision that allows a doctor to have final say in what medicines are ordered for a patient rather than have the state decide from a limited list of alternatives. We think this is essential for psychiatric medicines where the substitutes are not always comparable.

Criminal Justice Issues--(by Bob Corliss) Advocates urge more CIT training for police officers—On March 9 an array of mental health advocates gathered in Albany to urge the state legislature to add \$1 million to the state budget to expand Crisis Intervention Training (also called Emotionally Disturbed Persons Training) for local police officers. Last year the legislature added \$400,000 which went to support training in Syracuse, Hempstead, Newburgh, Utica and St. Lawrence County. There are now 15 communities in the state which have set up CIT/EDPRTS programs.

Last May in Schenectady, NAMI collaborated with the Schenectady PD, the county Office of Community Services and the State Division of Criminal Justice Services (DCJS) to sponsor CIT training here. The program, funded by a DCJS grant, enrolled about 24 city officers and others from surrounding departments.

NYPD Chief sparks firestorm—An internet tweet by a NYPD deputy commissioner created a brief social media brouhaha a few weeks ago when he tweeted “people off their meds r losing it & wiking into police bullets.” The deputy, Zachary Turin, said he was referring to a joint report by the Treatment Advocacy Center and the National Sheriffs Association that said a lack of mental health services has led to more persons with a mental illness being killed by police across the country. Turin was hit with a pile of twitter responses complaining about his language and suggesting police could do a better job by trying to de-escalate situations through CIT and not shooting people. Turin apologized, also on twitter.

NAMI-NYS promotes dialog on laws regarding insanity plea—Mental health advocates gathered by NAMI- NYS recently spurred a discussion about the need to reform existing state law on the so-called Insanity Plea. The law is in need of reform because defendants who successfully employ the mental health defense remain institutionalized much longer than if they accepted a guilty plea to the charges. Because of this—never knowing if or when you might be released, most defendants and their lawyers shun mental health pleas, except in cases where a homicide is involved. In all likelihood many more persons would benefit from the intensive psychiatric help they would receive in a hospital setting if they had a greater sense of how long they would be confined.

The advocates are looking at the practices of other states plus relevant case law and the inequities and injustices which the present system permits. A true reform effort would result in a system of care where more defendants would be able to access mental health services and not be adjudged criminals. And where eligible defendants would be provided fair notice as to the presumptive length of time they could expect to be confined in a psychiatric setting before being returned to the community.

Other government news--NY Daily News reported March 27 Gov. Cuomo and legislative leaders sought to wind up the budget talks shortly so a new budget can be enacted by the April 1 deadline. Issues over education aid and ethics reform still exist. Governor's proposed budget calls for \$440 million for services for the homeless over the next four years, most of it going to NYC, NY Daily News also wrote. \$220 million of that the governor originally proposed for rent subsidies for domestic violence victims, seniors, and working families who can't afford rent. One item not expected in the final budget is Cuomo's call for a minimum wage hike, which the Senate GOP would not support.

Advocacy at national level--

House and Senate Budget Resolutions Endanger Medicaid (From Andrew Sperling of NAMI national, March 24): Last week the House and Senate Budget Committees reported their proposed 2016 budget resolutions. These proposals call on Congress to change the Medicaid program into a block grant to the states, repeal the Affordable Care Act (ACA) and balance the budget within 10 years without adding tax increases. Both the House and Senate will be voting on the budget resolution this week, aiming to pass a final budget by March 28.

Currently states administer Medicaid, but receive an open-ended funding match from the federal government. Both the House and Senate budgets would replace this federal-state funding match with a lump-sum annual block grant, giving states flexibility to design their benefits, limit eligibility and increase cost sharing between the state and the person receiving Medicaid. Both budgets assume that the sequestration caps, or across-the-board spending cuts imposed in 2011, will remain in place. Simultaneously, the Senate budget proposes to cut domestic non-defense spending—which could include mental health research, services and supports—by \$236 billion below the caps set by sequestration.

The House and Senate budget resolutions change the way Medicaid is funded. In order to save at least \$400 billion over 10 years, the budget will allow states greater authority in meeting their specific population needs while controlling overall program costs. However, it would also repeal the current legal benefits associated with Medicaid for non-elderly adults with serious mental illness who are eligible for Supplemental Security Income (SSI). NAMI has consistently opposed proposals to convert Medicaid to a block grant because of the potentially devastating impact for those who rely on the program for critical treatment services, including prescription medications and support services such as case management and peer support.

Currently, Medicaid spending has the ability to adapt as program enrollment increases or as new, innovative treatments become available. If Medicaid were to be converted to a block grant, states would be limited to a lump sum of money each year. The result? Major pressure on states to continually cut costs by reducing eligibility for programs, reducing available services, or drastically cutting pay for medical and mental health providers well below already low levels.

The Obama Administration has made it clear that they oppose any proposal to convert Medicaid to a block grant. Nonetheless, NAMI will continue to monitor this process closely and will be posting action alerts.