Unfinished business
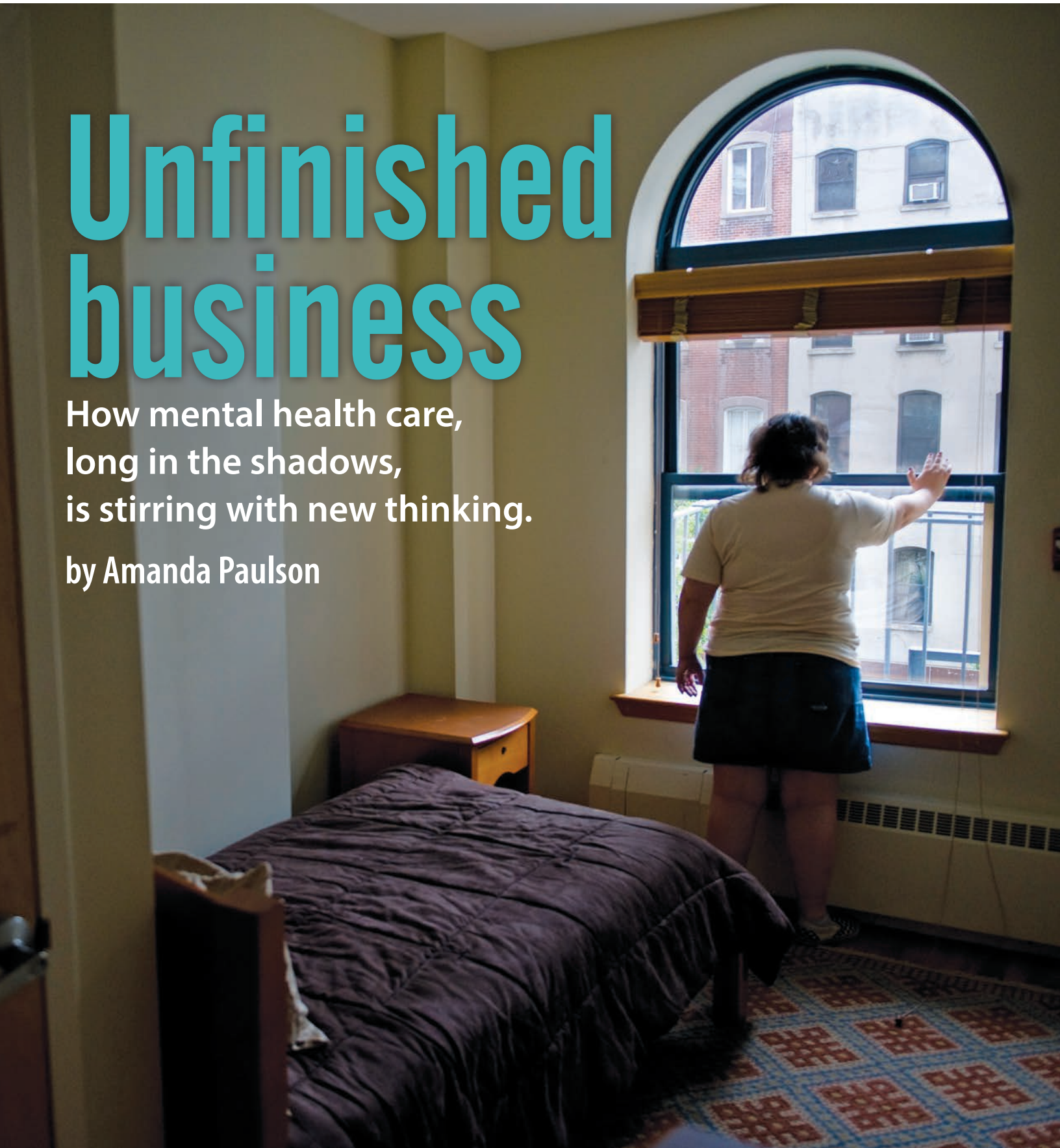
How mental health care, long in the shadows, is stirring with new thinking.

by Amanda Paulson

Mental health:
OUR UNFINISI

Massacres by mentally unstable shooters have focused attention on the inadequacies of the US mental health care system, in which less than half of the seriously ill can get treatment.

By Amanda Paulson / Staff writer

NEW YORK

Patti Sacher's daughter, Lisa, was 19 when she first started to show signs of mental illness.

"It was like getting hit from behind by a Mack truck," says Ms. Sacher, when Lisa, a bubbly, lighthearted college sophomore living in Madison, Wis., started to talk about hearing voices, showing signs of paranoia, and using drugs. Police, on one occasion, even had to drag her out of the middle of a busy street where she stood screaming at tormenters seen only by her.

When Lisa dropped out of school, Sacher and her husband acted on their feelings of love and responsibility for their daughter and tried to bring her home for treatment. But Lisa resisted, and they found out they had no authority to compel the school or anyone else to help: Lisa was no longer a minor. That helpless realization was just the beginning of a 17-year effort to help her.

Though they did eventually bring her home, Lisa (a pseudonym her mother uses) refused most treatment for her diagnosis of schizophrenia and would stop taking the medication prescribed for her because she didn't like the side effects and didn't think she needed it. She went to three residential treatment programs, but ran away each time. Her mother managed at least half a dozen times to get Lisa hospitalized, but the short stints did little good – she inevitably ended up endangering herself.

"I used to think it was only bad parents who had kids who ended up like that," says Sacher, who now volunteers for the New York City chapter of the National Alliance on Mental Illness, teaching a "family-to-family" class for those struggling with the same issues she has.

Sacher remembers being struck by an article in a newspaper asking people to help look for a missing elderly man with Alzheimer's disease: Some mental illnesses arouse sympathy and others blame, she says.

Sacher's frustrations with the mental health care system in this country are typical. It's a system nearly everyone agrees is fragmented, inadequate, and offers little help until someone reaches a crisis – and often not even then.

Now, after a succession of shooting massacres – by Adam Lanza in Newtown, Conn.; Jared Loughner in Tucson, Ariz.; James Holmes in Aurora, Colo.; and John Zawahri in Santa Monica, Calif. – the mental health care system is in the limelight to a degree it hasn't been in decades. In the case of Mr. Lanza, who killed 27 people, including 20 first-graders and his mother, before killing himself, there isn't much conclusive known about his mental-health history – and what information there is doesn't explain what might have caused him to commit such violence. It is clear he was troubled, and the shooting sparked a massive

'I used to think it was only bad parents who had kids who ended up like that.'

– **Patti Sacher,** who became a volunteer with the National Alliance on Mental Illness after her daughter's own lengthy mental illness

HED BUSINESS

At a Parachute NYC respite care facility, guests in a psychiatric crisis have an alternative to hospitalization.

outcry over the need for better treatment for the mentally ill.

President Obama called for a national conversation on mental health and sponsored a one-day conference on the issue in June, calling for more help for young people and veterans, in particular, and saying it's time to "[bring] mental illness out of the shadows."

Just a day after the Newtown shooting, blogger Liza Long published an article about her own experience with a mentally ill son that quickly went viral. Titled "I am Adam Lanza's mother," the blog was an impassioned plea for more discussion of mental illness and more options and support for those who struggle with it.

The Newtown shooting has started a national conversation about tougher mandatory commitment laws, tighter gun-control laws for people with mental illness, and the need for more funds. Some opponents of gun control seized on mental health care reform as a better way to respond to Newtown than stricter gun-control laws.

Advocates for better mental health care tend to see all the attention as a mixed blessing.

"On the one hand, they recognize the mental-health system needs all the attention they can muster," says Paul Appelbaum, director of the division of law, ethics, and psychiatry at Columbia University in New York. "On the other hand, the link to violence as a means to persuading people to provide more adequate levels of funding is misleading and likely to further stigmatize people with mental illness."

An overwhelmed system

Most agree that the current system is not adequate. A litany of statistics illustrates its shortcomings. Only 4 in 10 people with a serious mental illness have access to any treatment. The number of institutional public beds available for the mentally ill is 5 percent of what it was 50 years ago. Since 2009, about $4.35 billion in state funding has been cut from the mental health care system. Some 20 percent of people in prison have a serious mental illness. More than a quarter of adults living in homeless shelters have a serious mental illness.

No one, of course, is suggesting a return to the system of 50 years ago, when many people were involuntarily locked up in psychiatric wards for years. When such hospitals were closed in the 1960s and '70s, a community treatment system offering high-quality treatment in a less restrictive setting was supposed to take its place.

"The problem is that those resources never materialized in a way to compensate for the closure of the hospitals," says Liza Gold, a clinical professor of psychiatry at Georgetown University's School of Medicine.

While it's difficult to pin down exact costs, due to fragmented funding sources and varying quality of treatment, good community-based programs cost significantly more than warehousing the mentally ill in big psychiatric hospitals, says Frank Ochberg, a clinical professor of psychiatry at Michigan State University and a former associate director of the National Institute of Mental Health.

"Living in a community ... is more expensive," Dr. Ochberg says, though he also emphasizes that the psychiatric hospitals had negative effects on patients and employees, and needed to be shut down.

These days, the system isn't up to the task of dealing with the people experiencing a major mental-health crisis, and very few public programs offer support or preventive care before someone gets to that point. Family members, like Ms. Long, the blogger,

One of Parachute NYC's mental-health respite centers, situated on a tree-lined street in Manhattan, offers guests a calm environment for recovery.

talk of feeling scared and very alone when it comes to getting help for a loved one who they believe is on a downward trajectory – especially when the person doesn't recognize his or her own illness and refuses any help.

"It's unlike any other health-care system in this country," says Ron Hornberg, national director for policy and legal affairs at the National Alliance on Mental Illness. "It's geared toward not intervening until a person goes into crisis. Early identification, intervention, and continuous care are frequently not available for people. With any other medical disorder, if you waited until somebody was in crisis until you intervened, the death rates and costs would be much higher – but that's pretty much how the mental health care system functions in many parts of the country…. We don't have any comprehensive system of care in place, and by definition many of these people need care on an ongoing basis."

For Sacher, one of her biggest frustrations was one common to many families of the very seriously ill: Her daughter was putting herself in dangerous situations. At one point Lisa believed that the heroin she was injecting would be safer if she diluted it with aloe, and while she was homeless for a while, living on the streets of New York's East Village, she was raped and beaten. But, to use the common medical term, she "lacked insight" into her disease. She didn't believe she needed to treat it and she didn't like the side effects, like weight gain, of the medications doctors prescribed. And her mother had limited ability to force her to get treatment.

Can treatment be forced?

There is perhaps no more controversial subject among advocates of better mental health than forced treatment. The current bar to pass – that the person must pose an imminent risk to himself or others – can be very hard to prove in some states. Many family members are told their best option is to lie about exactly what was said or when it was said in order to get someone admitted to a hospital, if they believe a person needs immediate help and the illness is preventing them from seeking that help.

Others point out that mandated treatment is often unsuccessful and may only alienate the patient from family and friends. The current bar for mandatory treatment is appropriately high, they say, and making it easier to force treatment could lead to an infringement of civil rights.

"The problem isn't our system of legal compulsion; it's our mental-health system,"

says Dominic Holt, communications director for the Bazelon Center for Mental Health Law.

Anytime an incident like the Newtown shooting occurs, there's a push to make mandatory treatment easier, on grounds that it's needed to prevent violence. Mr. Holt and others acknowledge that a very small number of people may be both mentally ill and dangerous. But trying to screen out those individuals and force them into hospitals, before they've done anything wrong, would be akin to going into a poor community and rounding up young men who are flunking out of school or exhibiting some other trait that puts them in a group at risk for violence, says Holt.

"There may be people who are mentally ill and become violent, and you can't identify them [beforehand], but that's true of all people," says Holt. "And mental illness tells you almost nothing about the likelihood they'll be violent."

Indeed, people with a mental illness are far more likely to be victims of violence than to commit violence themselves, studies show. Holt, like many in the mental-health community, would like to see the biggest emphasis placed on getting support and treatment for people early on, before their illness hits a crisis stage. And he'd like to see money put into interventions with a proven track record – like the growing number of programs using the Assertive Community Treatment approach. ACT involves teams of professionals helping patients with wraparound services such as housing and employment, as well as treating clients' illness and getting them on board with treatment. ACTs also sometimes use supportive housing programs.

Saying the mentally ill are dangerous discounts the myriad other attributes of their individual personalities, says Jeffrey Swanson, a psychiatry professor at Duke University in Raleigh, N.C. "Mental illness is one thing people might have, but they're also varied in all the other ways that make

people inclined to commit violent acts…. [In treatment], you have to think about the whole person and the whole environment, rather than just think about what to do to fix what's wrong with the paralimbic system."

One of the most prominent voices on the other side of this debate is E. Fuller Torrey, founder of the Treatment Advocacy Center and author of "The Insanity Defense: How America's Failure to Treat the Seriously Mentally Ill Endangers Its Citizens."

Dr. Torrey, who has compiled a database going back to 1987 of what he says are "preventable tragedies" incurred by people with a mental illness (nearly 4,000 just in the past 10 years), believes the pendulum

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> **– Ron Hornberg,** of the National Alliance on Mental Illness, on the lack of a comprehensive mental health care system in the US

has swung too far in the direction of civil liberties, leaving many people aware of a family member who is deteriorating quickly, doesn't have the insight into his own disease to voluntarily seek treatment, and who may be a danger to himself or others, with no recourse to get help.

"You've got to clean up the commitment laws so that you can evaluate people [without their consent] before they commit a horrendous act," says Torrey. "And you need enough beds to put them in…. No one needs to go back to where we were [before mental institutions were shut down], but we're way below the minimum number."

Sacher, for one, believes that involuntary commitment is sometimes necessary. She credits New York's Kendra's Law – named for a woman pushed to her death in a subway station in 1999 by a man diagnosed with schizophrenia and off his medication – with ultimately helping her daughter gain insight into her illness and get on a track toward recovery.

Lisa was hospitalized six or seven times over the years, mostly after an overdose or if she was in a catatonic state. Finally, in 2002, Sacher got Lisa a court order for assisted outpatient treatment (AOT) under Kendra's Law, lying a bit about the dates of her last overdose to get it.

Mandated outpatient treatment (as opposed to hospitalization) is also controversial and, in some states, means very little: A person is under court order to get treatment, but with little to no enforcement.

"As a crisis-driven knee-jerk reaction, when a state says 'let's pass outpatient commitment laws' – if they don't put a good program in place, it won't do anything," says Dr. Swanson. In New York, though, Swanson and others agree it's been implemented relatively well, with expanded ACT teams in place to help people placed in treatment.

"If you understand better the goals and preferences of the person you're treating you can do a lot better job in treating them," says Holt of Bazelon, who would like to see more ACT teams in place but without the Kendra's Law mandate. (In New York, ACT teams serve both voluntary and AOT patients.)

That's the approach that finally worked for Lisa, says Sacher.

Outpatient focus that works

More than 17 years after she first became ill, in 2002, Lisa finally stayed with treatment long enough to begin to get insight into her disease. A big part of what helped was being in day treatment with others struggling with the same issues, and having a therapist help her focus on her dreams apart from her illness.

"It was helpful for her to be in a place where the focus of her counselor and therapist was to say, 'What do you want? Let's make a plan. What's your dream?' " says Sacher. "Not, 'What do your parents or doctors want? Let's get you there.' She always felt she was moving forward."

Lisa began teaching swimming to children, something she had done in the past and loved. She lives on her own, and she manages her relapses herself, with some awareness of when she's starting to become sick again.

Sacher is grateful for the shift, though she also regrets the many lost years, and wishes there had been the possibility both for mandated treatment and programs that targeted young people when Lisa first became ill.

"She went through 17 years of instability," says Sacher. "If we had had AOT when she first got sick, she would be functioning on a much higher level now…. Those were … years that took away from her true potential."

But that isn't always the case. For Ann, who has also struggled for years with mental illness, hospitalization made things worse.

Providing a parachute for a 'soft landing' is the idea behind Parachute NYC, which provides respite care to the mentally ill. Keith Aguiar (l.), assistant program director, talks with staff at one of the program's respite centers. Peer counselors, who have undergone their own recovery from mental crisis, help guests.

When Ann (whose respite care director asked the Monitor not to use her last name because of the social stigma of mental illness) went to New York's Bellevue Hospital Center to see her therapist in June, she was in the middle of a crisis episode, and her therapist immediately took her to the emergency room. The whole experience there – being shuttled back and forth between the psychiatric ward to a medical room, and feeling as if no one was listening to her – was confusing and terrifying, and she checked herself out, says Ann, a longtime New Yorker who works as a playwright. If she hadn't heard about a new option, entirely voluntary, with no forced treatment, she says she would have just gone home, even though she knew she shouldn't have been on her own.

"My whole thing is fight or flight," says Ann. "If I were faced with a situation where I had to stay, I would have left."

The place Ann went is a nondescript townhouse near Union Square in New York. One of two respite centers run by a new pilot program called Parachute NYC (a third is in the works), the eight-bed home welcomes any guests – the term "patient" is never used – who feel that they may be hitting a crisis point and need some support.

Staying in the warm, welcoming rooms is voluntary. No one is forced to take medication. Staff are peers – people who have their own experiences with mental illness, have extensive training, and often relate to someone experiencing a mental-health crisis.

Along with the respite centers, the program runs mobile teams that work with individuals experiencing a crisis in their own environments and mobilizes their social community of family and friends to support their treatment and foster long-term change in how they approach their mental illness.

The basic idea: Catch people early in the trajectory of mental illness and provide a "soft landing," whence the name "parachute."

The program's respite centers, one of which caters specifically to young adults, are an alternative to hospitalization for people approaching a crisis. "As the challenges become greater, [it gives them] some place to go that's not about an institution," says Trish Marsik, assistant commissioner for mental health at the New York City Department of Health and Mental Hygiene. "It will provide an alternative to hospitalizations here in New York City that we haven't had before."

The department pays for the program with

Ann says that for her, it was exactly what she needed: "Just knowing I had a room to myself, with a private closet and private bathroom, and knowing I could leave my suitcase by the door and if I decide to run out I can, no one is holding me down, no one is going to shoot me up with medication or tell me I'm crazy – I could relax on my terms."

She stayed for two weeks, and was there with six guests, all of whom bonded, she says. They cooked dinners and ate together, and attended many group classes. Ann attended art classes, creative writing groups, and sessions in which she and others worked on developing a "tool box" for themselves to help deal with their illness, sometimes writing about strategies that seemed to work, how they felt in different situations, and how to apply these insights to their lives.

"You don't have to go to groups, but over time, everyone was in the group," she says.

Having peers on staff who have dealt with their own mental illness and hospitalizations was also a huge support. "Everyone here has a diagnosis, and they're working professionals now," Ann says. "I met with a friend of mine a couple days ago, and she said 'you've found your swans.' I feel like I belong here. I'm with people I understand and they understand me, and there's no judgment."

The staff who work there say that the voluntary nature of Parachute is key.

"Self-determination is huge – to have one's dignity and be master of one's domain," says David, a peer counselor at the respite center near Union Square who says his experiences with hospitalization and the mental health care system allow him to connect with guests in a very immediate

evaluations are positive, it will become a reimbursable service through Medicaid, since it will probably be far more cost-effective to help people in a preventive way. The daily operating cost of respite care, for instance, is $272 per person. Costs vary across hospitals, but that's about one-third the cost of a night at a New York psychiatric hospital for someone with a diagnosis of schizophrenia.

The Brooklyn respite home, which targets people between the ages of 16 and 30, within a year of the onset of their illness, fills a particularly strong need, say Neckles and Marsik.

Currently, there are few resources for young people, many of whom are turned off by treatment programs filled with much older patients far along in their illness.

"There is a real opportunity here to change the trajectory of how these people will move through the system and what they'll experience," says Marsik. "These 16-, 17-, 18-year-olds today will look back in 40 years and have a completely different history with the system."

It's not just younger people Parachute helps. If she hadn't found Parachute, Ann says, she would have gone into the same cycle she's been caught in for the past 25 years – leaving her job, cutting herself off from people, disappearing until she felt stable again.

"If a therapist was forcing me to take medication I didn't want to take, I'd be belligerent. I wasn't helping myself," she says, noting that she does take some medication but prefers finding other ways to deal with her illness. She feels the support and tools she's gained at Parachute are already helping.

a federal innovation grant from the Centers for Medicare and Medicaid Services, and by partnering with eight providers to offer services. The Manhattan respite center is run by Community Access, a nonprofit that has long been meeting the needs of New York's mentally ill, and most of the mobile teams are run by the Visiting Nurse Service of New York.

Ms. Marsik is particularly excited about the pairing of the respite centers with the mobile teams, all of which include a social worker, a psychiatrist, and a peer trained in "needs-adapted treatment" – a model that is centered on the individual and his or her family and friends, goals, and needs. The program is relatively new in the United States but has had great success in Finland, where one long-term study of a model, used with first-episode psychotic patients, found that two years later more than 80 percent of patients had no residual psychotic symptoms, 84 percent had returned to full-time work or study, and only one-third had used antipsychotic drugs.

In other words: Patients were functioning well in the real world and didn't seem to be relapsing.

Staff at Parachute NYC, which began in January, hope to find similar results, firmly believing that a more welcoming, person-centered approach at the onset of illness can prevent more serious episodes and involuntary hospitalization.

> ## 'Self-determination is huge – to have one's dignity and be master of one's domain…. [I]t's lasting.'
>
> **– David,** a respite center peer counselor who was once hospitalized for mental illness

way. "Everyone tells you what you should be doing. When you come to those decisions on your own, it's lasting."

What Parachute is doing "is uncharted territory," says Jamie Neckles, the project manager from the city's Department of Health and Mental Hygiene.

A federal grant is funding the pilot program, but Ms. Neckles hopes that if

In the past, she's worked with some mobile crisis teams, but they scared her. Now, she's planning to use Parachute's team because she feels she can trust them. And she also likes knowing there's a hot line she can call if she wakes up in her nightmares – something that occasionally occurs – with people at the other end whom she knows, and who will understand.

Large psychiatric hospitals, like the former one in the Bellevue Hospital Center in New York City, were closed in the deinstitutionalization reforms of the 1970s. Outpatient treatment was supposed to replace them, but it was never fully funded.

"They've already printed off a list of different places for me to go," Ann says, preparing to leave the respite center to return to her apartment. "I want to start exercising again.... It's a miracle here, it truly is."

At this point, it's impossible to know whether the Parachute model – which has served fewer than 100 people and has

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>
> **– Ann,** a mentally ill guest at Parachute NYC, on why respite care works better than forced treatment

fielded 1,500 calls on its support line – will fulfill the hopes of supporters, but it serves a niche that most agree has too few op-

tions for voluntary preventive care that is patient-centered.

Violence focuses policymakers

Though mass shooters are the catalyst forcing the public to focus on mental health care, the reality, say psychiatrists, is that predicting the one person in thousands who will act on such violent impulses, even among those suffering from a serious mental illness, is nearly impossible. But, they say, the focus on the system is exposing how vastly inadequate it is.

"The irony is that something that could, in the short run, be bad, by increasing the stigma [of mental illness], is also an occasion to focus the minds of policymakers, and getting public support behind the mental health care system that could have long-term benefits," says Swanson.

But Swanson, Mr. Hornberg, and others hope that policymakers keep their eyes on the evidence-based practices that help people in the long term, rather than just managing a severe crisis with medication and short-term hospitalization.

For some people, whose illnesses keep them from being able to recognize their need for help, that may mean mandated treatment, says Hornberg.

But, he adds, "I believe that if you had a system that was more assertive and more inviting to people and focused more on early intervention, in many cases you would never get to that point. Situations wouldn't progress to where they're acute emergencies." ■

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