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# Learning to Live with the Voices in Your Head

By giving young people with schizophrenia more control over their care, a Columbia-led program aims to help them lead fuller lives.

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**Ambar Martinez** began experiencing paranoid delusions six years ago, around the time her father died of a heart attack. Then eighteen years old and a sophomore at Syracuse, Martinez had trouble accepting his death, and so her mind provided an escape hatch: her father wasn't really dead, it told her. Rather, her family and friends were orchestrating an elaborate hoax to make it seem like he had died, for the sole purpose of causing her pain. At her father's funeral, Martinez suspected that the other mourners were plotting to humiliate her. She also heard a voice in her head — a young man's voice, reedy and snide — that mocked her for crying, saying she was weak, pathetic, and foolish.

"I remember feeling disoriented at the service, but I knew the voice was real," recalls Martinez, who is now twenty-four. "I was angry that everybody else was acting like they didn't hear it."

When Martinez returned to Syracuse, her condition rapidly deteriorated. Until then a gifted student who juggled an active social life with membership in hip-hop and Latin-dance troupes and other artistic endeavors, she started skipping classes, avoiding her friends, and hiding in her dorm for days on end. She brushed off anyone who asked about her well-being, fearing they were scheming to harm her. Meanwhile, the voice in her head became louder and more persistent, criticizing her

every thought and action, telling her that she was ugly, stupid, boring, and despised. Martinez began to argue with the voice, sometimes yelling out loud to try to make it stop.

Eventually, as Martinez's behavior became increasingly alarming and disruptive, a guidance counselor overseeing a scholarship program she was enrolled in contacted Martinez's mother and helped to arrange for her admission to a psychiatric hospital in New York City. There Martinez received one of the most feared mental-health diagnoses: schizophrenia. The prognosis for anyone with the condition, doctors told her family, was bleak. She would need to take powerful antipsychotic drugs, which would likely reduce but not eliminate her delusions. Other common symptoms of the disorder, like social withdrawal and a lack of motivation, they said, were essentially untreatable.

"They made it sound like my life was basically over," says Martinez. "I was never going to finish school, get a good job, or find a partner — none of that. It sounded like I'd be lucky to attend to my basic needs and would probably always be at risk of suicide and homelessness."

And for a while, that's where it seemed Martinez's life was headed. She dropped out of college and spent the next year in and out of psychiatric hospitals. Each time she was sent home, Martinez would emotionally unravel, holing herself up in the small apartment she shared with her mother in Queens, wrestling day and night with paranoid thoughts and the cruel, taunting voice in her head. "I spent all of my time alone, doing nothing," she says. "The voice made it impossible for me to enjoy anything — impossible to find a moment of peace." Martinez also gained a tremendous amount of weight, a common side effect of antipsychotic medications, which made her feel that her body, like her mind, was no longer under her control. Therapy sessions went nowhere, as she refused to accept psychiatrists' appraisals of her condition. "I really wasn't convinced that I was mentally ill at all," she says. "When doctors would say I was delusional, I'd be like, 'And who the hell are you to say that my perceptions are any less real than yours?' Honestly, I thought it was bogus."

But then, during one of Martinez's numerous stays at Gracie Square Hospital in Manhattan, a social worker there recommended a program called OnTrackNY, which takes an unusually ambitious, all-hands-on-deck approach to treating young adults with psychotic disorders. The program, created and overseen by Columbia University

professors in conjunction with the New York State Office of Mental Health, employs large multidisciplinary teams of providers — psychiatrists, psychologists, nurses, education and employment specialists, peer mentors, and others — who work closely together to provide intensive, coordinated care to people in the early stages of schizophrenia, while also offering support to their families. OnTrackNY is guided by the belief that if psychotic disorders are diagnosed promptly and treated with a broad package of therapeutic and social supports, in combination with medication, their progression can be slowed or possibly even halted, enabling patients to live full and purposeful lives.

“We tell our participants there’s no limit to what they can achieve if they engage with us, which isn’t a message that many of them have heard from doctors or therapists before,” says Iruma Bello, a Columbia psychologist and OnTrackNY’s clinical-training director.

Getting patients to take charge of their own care, in part by allowing them to define the goals of treatment, is a cornerstone of the initiative.

“Many participants will show up not buying the idea that they have psychosis and bristling against the diagnostic labels that the medical establishment has applied to them,” says Ilana Nossel ’98CC, ’04VPS, a Columbia psychiatrist and OnTrackNY’s medical director. “Yet they might acknowledge that they’d like to get along better with other people, feel less frightened and alone, or go back to school, and so we’ll work with that. We’ll say, ‘OK, let’s put aside this whole issue of your diagnosis for now and instead focus on the goals you want to achieve and how to attain them.’”

Martinez recalls that when she first visited an OnTrackNY location at Elmhurst Hospital in Queens in the fall of 2017, she was still deeply psychotic. “I wasn’t sure if I could trust the people I met there,” she says. “I thought maybe they were out to get me, just like everybody else.”

But the OnTrackNY staff gradually drew Martinez in with a combination of empathy and persistence, checking in on her several times a week; visiting her at home when she felt too frightened to go outside or ride the subway; counseling both Martinez and her mother, who was struggling to figure out how best to care for her; and helping Martinez find an antipsychotic medication that worked better for her.

“One of the things I noticed in hindsight is that whenever they challenged my delusions, they were very gentle and subtle,” Martinez says. “Like they’d never say,

‘You’re not seeing things the right way.’ Instead they’d ask innocent questions to poke holes in my perspective and help me realize when I was seeing the world differently from everyone else. I think if they’d been more forceful, I would have walked.”

When, after a few months, Martinez brought up the prospect of returning to college, the OnTrackNY staff jumped into action, helping her research college-reentry programs.

“It was around that time a major shift happened for me,” Martinez says. “I was still hearing the voice and having some paranoia, but I felt more in control, like I was driving my life again. I even started to accept the fact that I might always hear this voice, and I felt like I might actually be OK with that. I remember talking to my therapist about what I’d do if the voice got too loud for me to hear a teacher in class, and we decided that I could always take a break until it got softer. And I was like, ‘Yeah, I can do this. Why not?’”



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**OnTrackNY** is the creation of a research team led by Lisa B. Dixon, a Columbia psychiatrist and schizophrenia expert. To date, it has served nearly three thousand adolescents and young adults, through a network of participating mental-health clinics and hospitals. State residents between the ages of sixteen and thirty who have developed schizophrenia or a similar psychotic disorder over the previous two years are eligible to receive care through the program, regardless of whether they have health insurance or the ability to pay.

“We’re targeting young people who’ve been diagnosed fairly recently because research suggests that the sooner someone is treated for psychosis, the better their prospects are for recovery,” says Dixon. Receiving care promptly, she says, increases the chances of people meeting their life goals, whether that involves living independently, attending college, holding a professional job, or raising a family. “Some people with schizophrenia may achieve a full recovery, and even those whose symptoms persist can learn to cope and thrive in mainstream society,” she says. “It isn’t like in the movies, where individuals with serious mental illness are always acting aggressively or unpredictably. You’ve probably met people with schizophrenia without even realizing it.”

The idea that people with schizophrenia might reasonably aspire to lead ordinary lives if they receive exceptional care is a novel one. Throughout most of the twentieth century and into the twenty-first, medical orthodoxy held that schizophrenia was an inexorably progressive disease that condemned most patients to a lifetime of disability. Although psychiatrists had long recognized that small numbers of people diagnosed with schizophrenia recover, they nevertheless thought that the disease’s course was beyond their control, in part because antipsychotic medications seemed to rarely, if ever, alter the condition’s fundamental trajectory. These drugs, when taken at high doses, can also cause side effects, like emotional flatness and cognitive decline, that many people find nearly as debilitating as the symptoms they suppress.

“Traditionally, mental-health professionals have regarded schizophrenia as a pretty grim and hopeless diagnosis,” says Dixon. “And some clinicians still hold that outlook today, even though the science, I’d say, no longer supports it.”

Dixon has been pushing back against what she sees as the medical establishment's fatalistic attitude toward schizophrenia since the 1990s. Then a young professor at the University of Maryland, she conducted research showing that intensive psychological and social support services, if delivered in a coordinated manner and with a dash of creativity, can help people with schizophrenia reclaim some of their former abilities. She found that simple things like teaching family members how to participate more effectively in their loved ones' care and introducing patients to others who were further along in their recovery could noticeably improve their prospects. Such interventions worked in part by inspiring patients to adhere to their medication regimens, which is a major challenge in caring for people with severe mental illness, Dixon says. They also helped pull patients out of the feelings of hopelessness, shame, and self-loathing that many had succumbed to after years of illness. "It's probably no surprise that if someone is constantly receiving a message that little is expected of them, they'll come to expect little of themselves too," she says.

From the beginning, Dixon's work was informed by her own family's experience. Dixon was twenty-two in 1981 when her older brother, then a brilliant and sensitive medical student, was diagnosed with schizophrenia. Following her brother's mental collapse, Dixon, along with her mother and four other siblings, spent years trying to arrange decent care for him, with frustrating results. "He was prescribed antipsychotic medications and essentially left to his own devices in my mother's Long Island home, with very little in the way of therapy or professional support," she says. "The concept of recovery, of having any kind of future to look forward to, wasn't even on the table." Dixon says her psychiatric career has in many ways been a direct response to her family's anguish, and to that of her brother, who has spent much of his adult life in state hospitals. "I want other people to get better care, and to have better opportunities, than he had," she says. "That's always been my North Star."

Early on in her career, Dixon earned a reputation as an astute observer of research trends and a clinical innovator. "It's one thing to show that a novel procedure works well in an academic hospital, where the providers are also researchers," Dixon says. "But will your plan work at scale, in community health centers run by people without lots of specialized training? That's a whole other ball game." This led to her being invited to participate in a landmark federal initiative in the mid-1990s to write new treatment guidelines for schizophrenia. She and several other prominent

psychiatrists published three influential reports between 1998 and 2010, part of a broader effort to update standards of medical care in fields that were thought to be lagging. The reports recommended that clinicians caring for people with schizophrenia expand their use of talk therapy, substance-abuse counseling, supported employment, cognitive-behavioral therapy, and social-skills training as vital complements to antipsychotic medications. The team's final report also introduced many American health-care professionals to an idea that had been floating around in scientific circles in the UK, Australia, and Denmark for a few years: that if coordinated care was delivered promptly, in the earliest stages of the disease, the progression of schizophrenia might be slowed down or stopped, sparing patients some of the worst ravages of the condition. A handful of clinical programs informed by this concept had already achieved preliminary success overseas. Dixon and her colleagues concluded that the idea was promising but needed further research to validate it.

"One of the key benefits of the approach was that people in the early stages of disease could be treated effectively with lower doses of drugs than was typical, which meant they'd experience fewer debilitating side effects," Dixon says.

Soon, two teams of US researchers — one led by Dixon and Columbia faculty and the other by John Kane of Zucker Hillside Hospital in Queens — received grants from the National Institute of Mental Health to develop and evaluate their own early-intervention services for schizophrenia, with a fresh twist: they would give patients an unusual degree of control over their own care. "We knew from experience that it's particularly challenging to get young people to adhere to treatment, so we wanted to design a program that they'd want to participate in, one in which they'd feel respected and heard," says Dixon. While Kane's group tested the new approach against traditional care in a network of health clinics in twenty-states, Dixon and her colleagues studied the logistical nuances of how such a program could be optimally operated and financially maintained. The dual-track project was so successful, with patients who received the experimental care consistently reporting fewer symptoms and less disability, that New York State health officials decided to step in and launch their own version of the program in 2013, two years before the study officially concluded. The initiative, to be administered by Columbia's psychiatry department and its affiliated New York State Psychiatric Institute, was dubbed OnTrackNY, and Dixon was immediately brought onboard to build it.

**Today,** OnTrackNY is a national model for schizophrenia care. One of the largest programs of its kind in the country (it has spawned imitators in several other states), it consists of twenty-five affiliate clinics and hospitals in fourteen New York counties, with another seven sites slated to begin offering services in 2023. When its current expansion is complete, OnTrackNY will have the capacity to enroll about seven hundred people annually, or approximately two-thirds of the estimated population of young people who are newly diagnosed with schizophrenia or similar psychotic disorders in the state each year. Officials at the New York State Office of Mental Health, which subsidizes the program and works with Columbia faculty to select partner sites based on demand, would like to see that number climb even higher.

“Our goal from the beginning has been to make OnTrackNY available to every young person in the state who needs it, and we believe we’re on course to achieve that goal within the next five years,” says Thomas E. Smith, the agency’s chief medical officer. State and federal agencies currently subsidize about half the $1,500 monthly cost of the average patient’s treatment. (Treatment usually lasts about two years.) Smith says that his office hopes to persuade the federal government and private insurers to cover more of the cost, which would enable the state to make the services even more widely available.

While it is too soon to know how young people in OnTrackNY may benefit over the long term, the state’s investment appears to be paying off. At least while patients are in the program, the initiative has been shown to improve their lives by every important measure, reducing their chances of experiencing psychotic episodes, hospitalizations, suicidal feelings, violent impulses, anxiety, and depression. Many patients also reconnect with academic, professional, and creative interests that they had given up when they became ill; by the end of their treatment, more than two-thirds are enrolled in school or working again.

“We’ve had participants go back and graduate high school and college, earn advanced degrees, and land high-level jobs in fields like engineering, finance, and public relations,” says Bello, the Columbia psychologist and program codirector. “Their successes have been eye-opening.”

Bello, who oversees clinical training for all mental-health professionals in the OnTrackNY network, says that when she was in graduate school in the mid-2000s, psychologists were taught to steer people with schizophrenia toward sheltered work opportunities, such as highly supervised low-wage jobs intended for the disabled: “I

was trained to think that you didn’t want to expose people to much stress or else you’d accidentally set them back.” Even now, Bello says, new clinicians learning the OnTrackNY model often need to be taught to support their patients’ more aspirational goals. “I tell trainees, ‘Look, we don’t have a crystal ball. Believe in this person, and don’t try to predict what is or isn’t possible based on what you’re seeing at this moment.’”

One reason OnTrackNY works so well, its organizers say, is that the program is reaching people with schizophrenia very quickly. Whereas it typically takes a year or more for someone with the condition to receive professional help, on average a patient enrolls in OnTrackNY just seven months after their first psychotic episode, which means they are receiving treatment when the disease is still in its early stages. Dixon credits this in part to OnTrackNY’s community-outreach efforts to help teachers, clergy, police officers, social workers, and others learn to spot the warning signs of schizophrenia. “People who are experiencing psychosis often don’t exhibit it in obvious ways or talk about it,” she says. “They might just withdraw into themselves, seem emotionally flat, stare off into space for long periods of time, or speak in disorganized ways.”

And then there’s the matter of accessibility: every OnTrackNY location is a one-stop shop where participants can visit a large team of providers, all working in close coordination, as frequently as several times a week.

But the secret to making everything come together, say Dixon and her colleagues, is that OnTrackNY providers treat patients as equal partners in their care, which means giving them a say in nearly every clinical decision. This can include seemingly small details, like choosing which of their family members participate. Or it can involve weightier matters, like decisions about medication. Many patients choose to reduce their dosage in order to minimize side effects, even if that means that their psychotic symptoms will not be completely eliminated. “Our clinicians will of course offer their professional assessments,” says Dixon. “But they’ll also listen to the participants’ preferences and ultimately support them.” The benefits of such a collaborative approach to health care are well documented, with studies showing that patients tend to feel more empowered, hopeful, and satisfied when doctors involve them in treatment decisions. This is true especially in the context of mental-health care, where patients expect to have their personal and emotional needs met. And based on the testimonials of former OnTrackNY patients, this certainly seems to be true for people with schizophrenia.

Story after story goes like this: Having endured an unspeakably terrifying, bewildering, and alienating emotional journey, a young person is in short order hospitalized, diagnosed, medicated, and discharged without ever fully comprehending what has happened. In follow-up appointments, doctors insist that they accept their diagnosis and nag them about taking their pills. But the young person doesn't want to identify as *schizophrenic*. They want to be seen as normal. They want to go back to school, earn money, hang out with friends. And the pills are causing them to gain weight, to feel lethargic and mentally foggy, and to have uncomfortable muscle spasms. *The doctors could be wrong about my diagnosis anyway*, they think. *Maybe it's just anxiety or depression or PTSD. I can handle this on my own if I buck up — I got this.* Eventually, they stop showing up for appointments. They skip doses. And they wind up back in the hospital.

The creators of OnTrackNY have learned to avert such crises by meeting schizophrenia patients where they are and by assisting them on their own terms, in ways that are immediately relevant to their lives. Rather than addressing patients' mental illness head-on, providers may initially help them develop strategies to ignore the voices in their head, to brave a walk down a crowded city street where everyone seems to be staring at them, or to mitigate their drug's side effects with physical exercise. As a result, OnTrackNY providers find, patients begin to reengage with life, to look forward to the future, and to feel that they are the masters of their own destiny again — despite in many cases still struggling with delusions or hallucinations. They keep coming back for appointments. They take their medicine. And eventually they open up to the possibility that they have a severe mental illness and start to learn about it. Slowly, they get better.

"I think one of the most powerful things about our project is we've flipped the script on the conventional idea that a person has to internalize psychiatrists' definition of their illness as the first step in treatment," Nossel says. "When I was in school twenty years ago, I was taught that accepting one's diagnosis — or 'achieving insight' about one's situation, as we called it — was a prerequisite to making progress. If a patient achieved insight, then their symptoms might diminish. And then they could start thinking about pursuing activities like school or work. But we've shown that's just not necessary. People can do remarkable things while still experiencing moderate levels of psychosis. And it's the very process of living, of reconnecting with the things that give their lives meaning, that starts them on the road to recovery."

**For Ambar Martinez,** a love of learning led her back out into the world. First, with the support and guidance of OnTrackNY staff, she attended John Jay College of Criminal Justice and completed her bachelor's degree. "That was a scary step," she says. "But I had to do it." Then it was on to the New School, where she earned a master's in philosophy in May 2022. Now she's pursuing a career as a mental-health advocate. "I want to create webinars and other training materials that will help providers understand how people with serious mental-health diagnoses really experience the world," she says.

A quick-witted, sensitive, and stylish young woman with two-tone hair and a closet full of 1980s-new-wave-inspired clothing, Martinez is currently living in New York City and working two part-time jobs. She still hears the voice in her head. It is her constant companion, quieting only when she sleeps. She also struggles with paranoia and intense mood swings, despite taking antipsychotic medication. But her relationship to these symptoms has evolved, she says. Whereas she once felt imprisoned by them, she now views them with detachment and derision, like bad neighbors one has long ago learned to tolerate. Listening to music on headphones partially masks the voice; dance and movement classes help stabilize her mood. She holds out hope of eventually liberating herself of psychosis altogether. "Having read Freud and Lacan, I suspect that there's an element of childhood trauma behind all of this," she says. "I need to delve deeper into my issues. Anything's possible."

In the meantime, her jam-packed life is its own form of therapy. Since finishing treatment at OnTrackNY, she's also self-published a novel about a young woman trying to make sense of her hallucinations, launched a blog, and worked at OnTrackNY as a peer specialist, mentoring others who have recently been diagnosed with schizophrenia. "When I talk to young people, I tell them this isn't going to be easy," she says. "But even if your symptoms never go away, there's so much you do still control. You can give your symptoms space to exist, let them walk beside you, while you go forward."

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