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U.S. NEWS

Drugged as Children, Foster-Care Alumni Speak Out

Use of Powerful Antipsychotics on Youths in Such Homes Comes Under Greater Scrutiny

By LUCETTE LAGNADO

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Today, Chris Nobles refuses all drugs. *Miranda Harple for The Wall Street Journal*

MECHANICSBURG, PA.—As a teenager in foster care, Chris Nobles was on a steady diet of psychiatric drugs—an antidepressant, an anti-seizure medicine and a powerful antipsychotic.

"It felt like having a very heavy blanket pressed against my mind," he recalls.

Mr. Nobles became a ward of the state of Pennsylvania at age 15, and for nearly three years, he says, doctors treated his depression and bouts of uncontrollable anger with the drugs.

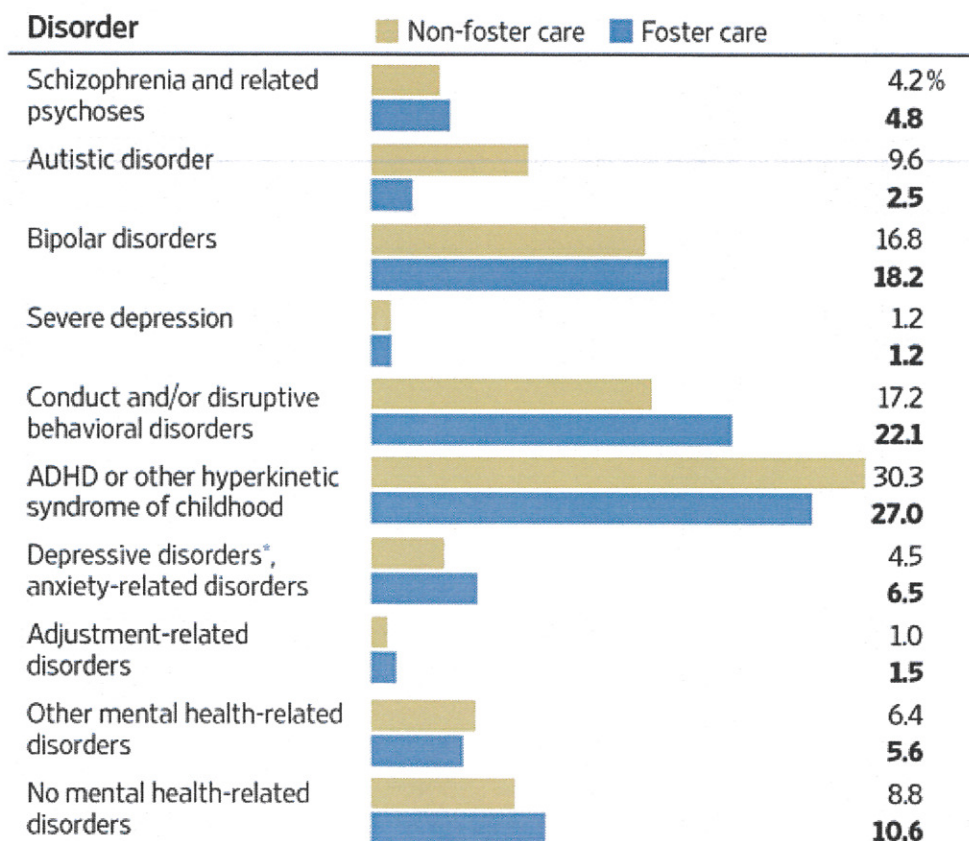
Now 23 years old, Mr. Nobles lives on his own and doesn't take any medication. ("Not even a Nyquil," he says.) He has a full-time job training foster-care case workers and dates a woman from his hometown. And he has joined a wave of foster-care alumni across the nation sounding the alarm about how freely psychiatric drugs, including strong antipsychotics, are doled out to kids.

Mr. Nobles and others like him have become forceful voices in the growing debate over how such children are medicated. The past decade and a half has seen an upsurge in strong antipsychotic drugs prescribed for children in Medicaid and foster care. The inspector general of Health and Human Services, the federal agency that oversees Medicaid payments, has launched an inquiry into such prescriptions. And the American Psychiatric Association has warned against the drugs' overuse.

Now, with roughly 20,000 young people being emancipated from foster care each year, many are anxious to speak out.

Medicating the Young

Distribution of diagnostic groups among youth ages 6-17 receiving antipsychotic medications, Medicaid fee-for-service claims, 2009



*Other than severe depression

Note: Disorders are listed by the severity of diagnosis. Individuals were assigned to the category reflecting highest-listed diagnosis.

Source: Stephen Crystal and Ece Kalay, Center for Health Services Research on Pharmacotherapy, Chronic Disease Management, and Outcomes The Wall Street Journal

Several states, including Ohio, Pennsylvania, Nevada and Arkansas, have created youth advisory boards made up of current and former foster care kids who weigh in on issues surrounding the system, including the use of psychiatric medicines.

And last spring, the Senate Finance Committee invited former foster children to Washington to a roundtable discussion on psychiatric drugs.

"We used to have to beg to have young people at the table," says Celeste Bodner, founder of Foster Club, an Oregon-based organization that works with foster youth and alumni. "These young people know...that meds alone aren't the answer—it doesn't take care of the demons."

Overseen by state and local governments, foster care provides temporary placement for minors unable to remain in their own homes. They can live in individual foster homes, in group homes, or other institutional settings. Nationwide, there were approximately 400,000 children in foster care in 2012, according to the Department of Health and Human Services.

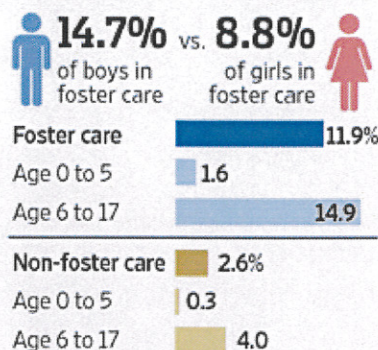
Antipsychotics, drugs dispensed for a broad array of diagnoses, have ignited a wave of debate—most recently over their use in poor children and the billions that they cost the Medicaid and Medicare systems annually.

Most scrutiny centers on a new class of antipsychotics sold under such brand names as Abilify, Seroquel, Risperdal and Zyprexa.

Based on 2009 data from Medicaid and private insurers, Stephen Crystal, a professor of health-services research at Rutgers University, estimates that 12% to 13% of kids in foster care take these medicines. That compares with about 2% for children on Medicaid but not in foster care and about 1% for those with private insurance.

Different Treatment

Percentage of youth receiving antipsychotics* through Medicaid



*Based on 2009 data
Source: Stephen Crystal and Ece Kalay,
Center for Health Services Research on
Pharmacotherapy, Chronic Disease
Management, and Outcomes
The Wall Street Journal

While originally hailed as safer and more tolerable than predecessor drugs such as Thorazine and Haldol, the newer generation of antipsychotics, often called atypicals, has spawned a growing body of research about potential side effects. These, say researchers, can include sudden and severe weight gain, increased risk for diabetes and movement disorders.

Atypicals, with their strong sedative powers, were originally intended for the narrow segment of adults with psychotic conditions like schizophrenia. The Food and Drug Administration only sanctions their use for kids diagnosed with schizophrenia and conditions such as bipolar disorder and irritability associated with autism. But physicians can also prescribe these medicines "off label" to combat behavioral issues in children—some as young as two years old.

Some doctors stress that the drugs are helpful in treating children with certain aggression and behavior illnesses. Yet many are concerned that the use of antipsychotic drugs, particularly among those in custodial care, has gone too far.

According to Prof. Crystal's research, the largest diagnostic groups receiving the drugs in foster-care in 2009 were those with disruptive-behavioral disorders and attention-deficit/hyperactive disorders.

"These diagnoses involve difficulty focusing attention or controlling behavior—but that is different from not being in touch with reality," a key element of psychosis, he says.

To be sure, some doctors see considerable value in the use of antipsychotics on children in custodial care. Dr. Christoph Correll, professor of psychiatry at Hofstra University's Zucker Hillside Hospital, maintains that

antipsychotics can effectively combat the violent, aggressive behavior some foster kids display. The drugs "generally work fast, which is often desired when kids are at risk of being suspended from school for their behaviors," says Dr. Correll. "In these situations, having to wait for a therapy appointment is not an option."

The popularity of such drugs helps to account for their blockbuster sales. In 2011, antipsychotics rang up \$18.5 billion in U.S. revenues, according to IMS Health, rising from \$12.9 billion in 2007. Sales dipped in 2012 as cheaper generics came on the market.

Of all prescription drugs sold in the U.S., Otsuka Pharmaceutical Co.'s Abilify boasts the biggest sales by dollar, ringing up \$5.87 billion in sales in 2012, according to IMS Health.

Manufacturers all say they strongly encourage doctors to adhere to the FDA's prescription guidelines. A spokesman for Otsuka says the company "never promotes use in pediatric patients" beyond the FDA guidelines. A spokesman for AstraZeneca PLC, maker of Seroquel, said the drug is safe and effective "when used in accordance with the FDA-approved indications." A spokesman for Eli Lilly & Co., maker of Zyprexa, said it was committed to "promoting our medications only for approved uses and within the scope of prescribing information approved by the FDA." Janssen Pharmaceuticals Inc., a unit of Johnson & Johnson that makes Risperdal, said in a statement: "Because children in foster care are particularly vulnerable to mental health problems, we support the creation of policies to protect their interests."

In September, the American Psychiatric Association urged its members to prescribe antipsychotics only to kids with serious psychotic disorders. Last year, the Inspector General for the U.S. Department of Health and Human Services launched a probe in five large states to review use of the drugs among minor Medicaid recipients.



Jen Hope says she was overmedicated in foster care. *Brian Widdis for The Wall Street Journal*

That's where the chorus of foster-care alum is chiming in.

Jen Hope, a 26-year-old foster care alumna who lives near Detroit, was part of the group chosen to share her experiences with the Senate committee.

Ms. Hope rattled off a list of some of the medications she took on and off over the years: antipsychotics Abilify and Seroquel as well as three antidepressants, a drug for attention deficit disorder and an anticonvulsant.

"Was this really necessary?" she asked during her appearance.

Ms. Hope, a college student and single parent, acknowledges that she struggled with serious emotional issues. But she is also critical of the way her problems were diagnosed and treated. At various points, she says, doctors said she suffered from depression, attention deficit disorder and bipolar disorder.

"How do you develop as a person and find out who you are when you have been given all these diagnoses?" she asks.

Stories like hers are prompting introspection in the medical community. "There is a consistent story here—it may not be 100%, memories are tricky—but they are saying what we really need to think about," says Dr. Glenn Saxe, chairman of child and adolescent psychiatry at New York University-Langone Medical Center. The recurrent message, he says, is "anger at not being treated well...by psychiatrists who don't even ask questions, and then give them a medicine."

Prescribing the drugs "seems too easy, too convenient," adds Dr. Gail Edelsohn, a psychiatrist at Community Care Behavioral Health Organization, a nonprofit managed-care company in Pittsburgh. "First, understand what is triggering the aggression."

Recollections from foster alumni are highly nuanced—and not all are entirely negative. Twenty-year-old Sharanda Crews, of Jonesboro, Ark., says the medications she took as a foster kid, including Seroquel, did some good. Diagnosed with depression and bipolar disorder, "I was always fidgeting," she says, describing herself as the type of child who would be "bouncing off the walls." Seroquel calmed her down, she says. But Ms. Crews, who remains in foster care under a state program that covers wards until age 21, says it also left her feeling as if "I were watching someone else live my life."

Efficacy issues aside, potential side effects are a concern. These can include obesity, elevated blood-sugar levels, and possible increased risk for diabetes, says Prof. Crystal of Rutgers. Perhaps an even greater threat, he says, are the "unknown unknowns," such as the impact these drugs may have on brain development in young children. While no relevant studies have been performed to date, "the younger the child, the more concerned you are," he says.

Dr. Correll of Zucker Hillside Hospital in Queens, New York, has spent years researching side effects of atypical antipsychotics. One 2009 report, studying 272 children and published in the Journal of the American Medical Association, showed that most subjects gained as much as 10 to 20 pounds after only 11 weeks on the drugs. A control group that didn't receive antipsychotics showed no significant weight changes.

The leading atypical makers cite the risk of weight gain in their literature and encourage doctors to monitor patients' weight.

Dr. Correll, who has received funding from several makers of antipsychotics, says it is impossible to know whether taking antipsychotic drugs as a child ultimately increases the risk of premature death. That, he says, is "the million dollar question."

Some states have taken action. In Nevada, the state Legislature in 2011 passed a Foster Care Bill of Rights that gives foster kids the right to refuse medicine that "makes you feel bad," according to language

in the law crafted for young people. In Texas, doctors are now required to check in with the state before prescribing antipsychotics to any child under three.



Dashun Jackson now works with foster kids. *Michal Czerwonka for The Wall Street Journal*

A key proponent of the Nevada measure was Dashun Jackson. Mr. Jackson, age 21, worked with other foster-care kids to help enact the bill. The 2011 law comes in two versions—one for adolescents, and another written in language even a young child can understand.

Mr. Jackson recalls his own yearning to say "no" when he was growing up. He entered the foster-care system at 14 after leaving what he says was an abusive home.

Foster care brought its own torments. He says he spent years on Seroquel, the antipsychotic, as well as the antidepressant Prozac. Seroquel would help him sleep at night, he recalls, while Prozac revved him up. The overall effect was so jarring he struggled to stay focused in school. "It was like I was in class but I wasn't in class," he says.

Mr. Jackson, who shared some of his medical records with the Journal, says he would skip his medicines for days. "I didn't like what they were doing. I was emotionless; I couldn't feel," he says.

When Mr. Jackson turned 18, he placed himself under the care of a doctor who weaned him off the medicines. For a change, he says, he was heartened that someone in the psychiatric establishment made an effort to help him out of a fog.

Raymond Giddens, a licensed social worker who ran the group home where Mr. Jackson lived for several years, says the young man had serious emotional issues. The medications, he believes, "helped him more than hindered him."

Yet Mr. Giddens is also critical of the treatment Mr. Jackson received. He confirms that psychiatrists rarely tried to explore what was triggering the young man's distress. "We were with them for five minutes, and they were putting him on medication," Mr. Giddens says. "They didn't talk to Dashun."

Lisa Ruiz-Lee, director of the Clark County Dept. of Family Services, the agency in charge of foster care in the Las Vegas area, says Nevada had made several reforms in recent years to put more emphasis on kids' mental health care. "But there is still more to be done," she says.

Mr. Nobles, the Pennsylvania foster-alum-turned activist, recounts his time in foster care as a blur of institutional and quasi-institutional homes, and, of course, medication. He says his drug regimen included Abilify, Zoloft and Depakote, an anti-seizure drug. The medicines didn't necessarily work, he contends—either to control his anger or quell his sadness.

"They would have given me a billion milligrams of whatever, and I still would have known that I was unadoptable," says Mr. Nobles, who shared some of his medical records with the Journal. He entered the foster-care system when he was almost an adult, at 15.

"I am a large, 6-foot-2 black male—who would take the risk?" he says.

Visits to psychiatrists seemed to bring him little relief. "Fifteen minutes was very generous," he says of his brief sessions with clinicians, echoing a complaint common among foster kids.

"How are you feeling?" Mr. Nobles remembers being asked. "I would say 'good,' and I was on the meds and I would say 'bad,' and I was on the meds."

Recalling those days recently, over a hamburger lunch at a Friendly's in Mechanicsburg, Pa., Mr. Nobles said that being on the drugs turned him off to the medical system. He now tries avoiding doctors altogether.

The drugs, he says, didn't even prevent his occasional angry outbursts.

One day, he says, he threw a chair at a classmate. He missed but hit a teacher who, mercifully, he says, didn't press charges. Looking back, he believes the medicines "didn't save me from almost ruining my life."

Still, he knows he is among the lucky. A study led by the University of Chicago on foster alumni in Illinois, Wisconsin and Iowa found that by age 26, fewer than half, 47%, were employed; most of those who worked earned less than \$12 an hour. Many had been homeless at some point.

These days, Mr. Nobles has a job helping train caseworkers at a center run by the University of Pittsburgh's School of Social Work.

In one training exercise, Mr. Nobles likes to tell students the story of Daniel, who enters the system as an adolescent, is plagued by anger issues and outbursts and wades through a raft of diagnoses and medicines. Mr. Nobles asks his pupils what they think could be done to help Daniel.

As he goes around the room, the answers generally suggest that "Daniel" is a tough, maybe even a hopeless, case.

Finally, he admits, "That Daniel is me."

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Corrections & Amplifications

Jen Hope told a U.S. Senate committee that she felt she had been overmedicated in foster care. A caption accompanying an earlier version of this article incorrectly stated that Ms. Hope found the drugs helpful. Also, Lisa Ruiz-Lee is director of the Clark County Dept. of Family Services, the agency in charge of foster care in the Las Vegas area. An earlier version of this article incorrectly identified her as Lisa Ruiz-Jackson.

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