One Drug or 2? Parents See Risk but Also Hope

By Alan Schwarz
New York Times
Nov. 14, 2014

CONCORD, Calif. — Every time Matthias is kicked out of a school or day camp for defying adults and clashing with other children, his mother, Joelle Kendle, inches closer to a decision she dreads. With each morning of arm-twisting and leg-flailing as she tries to get him dressed and out the door for first grade, the temptation intensifies.

Ms. Kendle is torn over whether to have Matthias, just 6 and already taking the stimulant Adderall for attention deficit hyperactivity disorder, go on a second and more potent medication: the antipsychotic Risperdal.

Her dilemma is shared by a steadily rising number of American families who are using multiple psychotropic drugs — stimulants, antipsychotics, antidepressants and others — to temper their children's troublesome behavior, even though many doctors who mix such medications acknowledge that little is known about the overall benefits and risks for children.

In 2012 about one in 54 youngsters ages 6 through 17 covered by private insurance was taking at least two psychotropic medications — a rise of 44 percent in four years, according to Express Scripts, which processes prescriptions for 85 million Americans. Academic studies of children covered by Medicaid have also found higher rates and growth. Combined, the data suggest that about one million children are currently taking various combinations of psychotropics.

Risks of antipsychotics alone, for example, are known to include substantial weight gain and diabetes. Stimulants can cause appetite suppression, insomnia and, far more infrequently, hallucinations. Some combinations of medication classes, like antipsychotics and antidepressants, have shown improved benefits (for psychotic depression) but also heightened risks (for heart rhythm disturbances).

But this knowledge has been derived substantially from studies in adults — children are rarely studied because of concerns about safety and ethics — leaving many experts worried that the use of multiple psychotropics in youngsters has not been explored fully. There is also debate over whether the United States Food and Drug Administration's database of patients' adverse drug reactions reliably monitors the hazards of psychotropic drug combinations, primarily because only a small fraction of cases are ever reported. Some clinicians are left somewhat queasy about relying mostly on anecdotal reports of benefit and harm.

"When I prescribe multiple psychotropics, there's a good reason — even if I don't know the exact interactions or efficacy, there's a clinical reason to give it a shot," said Dr. J. Wesley Boyd, a psychiatrist at the Cambridge Health Alliance in Massachusetts. "But saying, 'The last time I gave x, y and z to someone they did fine,' that's not science."

Added Dr. David Rubin, a pediatrician at the Children's Hospital of Philadelphia, "We don't perform trials over the course of 10 years to see what our decisions now mean for later."

This uncertainty further polarizes debate among those who denounce overmedication of children and those who want suffering youngsters to receive potentially helpful treatments. Parents like Ms. Kendle, 26, get caught in the middle, having to decide what is best for a child, navigating societal and medical pressures.

"I want to know more about what it means for him to be on two medications, and no one can really tell me," said Ms. Kendle, a single mother in Concord, 30 miles northeast of San Francisco.

"It makes me angry looking for solutions," she added. "I know there's a sweet little boy in there. Yes, we don't know five, 10, 15 years down the line. But what about Monday morning?"

Some would consider Matthias a textbook candidate for combined treatment. His rages have overwhelmed schools and child care programs for years, and he is already struggling in first grade. He

and his mother — a medical technician whose typical workday drawing blood lasts from 7 in the morning until 4 p.m. — share a cramped and clamorous three-bedroom ranch house with her sister and brother-in-law and their spirited children, ages 3 and 6 months. Matthias is having nightmares and bladder-control issues.

Matthias can be wonderfully loving, nuzzling his sandy blond head into his mother's chest and turning his blue eyes up toward her in glee. But without warning, he can explode into fits of anger and despair. His mother has tried several behavior modification strategies and parenting techniques to only modest effect.

The Doctor's Office

Matthias's summer had deteriorated quickly. On his first day of science camp this June, Ms. Kendle received several phone calls about his refusing to join activities, not eating his lunch and bolting from adults trying to corral him. In early July the camp said he was not welcome back.

This was alarmingly regular for a boy with little regularity in his life. Ms. Kendle had him when she was 20, married his father four months later, and was divorced about six months after that. (The father has no contact with Matthias.) Increasingly aggressive and uncontrollable, Matthias was dismissed from three preschool programs before he turned 5, which led to his taking medication for A.D.H.D. Their home became even more chaotic when Ms. Kendle's sister's family needed to move in.

Last year, Ms. Kendle took Matthias to a local behavioral pediatrician, Dr. Lawrence Diller, and asked him to monitor her son as kindergarten brought greater demands. His triggers are both unpredictable and inexplicable: Water from a faucet turning hot too slowly, or his mother parking in the wrong spot, can send him into fits from which he does not recover for the rest of the day.

Often filling his worksheets with scribbles of frowning faces, Matthias barely made it through kindergarten. Then the disaster of science camp made Ms. Kendle fear first grade even more, leading her back to Dr. Diller's office in mid-July, more desperate than the year before. (She permitted Dr. Diller to record their conversation for this article.) The doctor floated an option: adding Risperdal, which has shown promise in tempering disruptive behavior in some children.

"For Matthias, who might feel at times overwhelmed or anxious, he'll probably experience that less," Dr. Diller explained to her. "But also more importantly the level of distress and the level of his anger will be decreased by the drug."

Ms. Kendle asked, "Do you know the long-term effects?"

Dr. Diller explained Risperdal's links to weight gain and diabetes, its unclear long-term effects on developing brains, and that its interactions with stimulants like Adderall had barely been studied. He acknowledged that he had never prescribed both medications to a child so young and cautioned against any quick diagnoses or decisions.

Dr. Lawrence Diller, a behavioral pediatrician, with Matthias and Ms. Kendle. The doctor is monitoring Matthias as his mother tries to decide if the drug Risperdal should be added to her son's treatment regimen. Credit Jim Wilson/The New York Times

"He's got M.S.D. — Matthias Specific Disorder," he said. "I'll see you in a few weeks."

At that early August appointment, Dr. Diller advised Ms. Kendle to delay the Risperdal decision until Matthias spent a few weeks in a mainstream class. Perhaps he would turn a corner. But if his behavioral and academic struggles continued, the school might recommend a special education track, which Ms. Kendle did not want. Then the added medication might be worthwhile, Dr. Diller said, in an attempt to avert the move.

Later that afternoon, as on most days, Matthias spent time with family members at home, where the overgrown backyard teemed with toys: a tire swing, a jungle gym, a trampoline. Matthias played amicably for two hours before taking out his kindergarten graduation present, a remarkably docile

10-inch rat, which he lovingly stroked and let crawl up his shirt, providing more than 30 minutes of ticklish delight. He later discovered an inchworm on a leaf and was entranced for almost 20 minutes.

The serenity was shattered a few minutes later, though, when Matthias decided he wanted to play with his mother's bouquet of shiny, jingling keys that were dangling from a nail beside the front door.

"Now Matthias, you know you're not allowed to play with my keys," Ms. Kendle said calmly. He continued to fiddle with them while making no eye contact. She warned him again to make a better decision, after which he looked at her more mischievously. Then he took the keys and ran.

Ms. Kendle chased him into the kitchen and coolly told him to go to his room for five minutes. He finally did so, kicking and screaming.

As his wailing pierced the walls, Ms. Kendle returned to the couch and said, "You just met the other Matthias."

Risperdal, known as risperidone in its generic form, is approved by the F.D.A. as treatment only for autistic children under 10. Its expanding off-label use in young children like Matthias has been quite controversial, partly because most studies identifying behavioral improvement were underwritten by pharmaceutical companies, including Janssen, Risperdal's manufacturer. Current American Academy of Child & Adolescent Psychiatry guidelines on antipsychotics state: "Much is still not known about the efficacy, tolerability, and long-term safety of these drugs in young people."

Combining an antipsychotic with another psychotropic medication might help an individual child, the guidelines say, but the practice "has not been studied rigorously" and "should be avoided if possible."

Many mental health providers, however, have decided that struggling children and families cannot wait for F.D.A. approval. At the psychiatry academy's annual convention in October, Dr. Boris Birmaher, the director of the child and adolescent anxiety program at the University of Pittsburgh Medical Center, told one audience of clinicians, "Just because the F.D.A. hasn't approved, it doesn't mean it isn't good."

"You cannot tell the family, 'Come back in five years and we'll treat you with this medication' until the F.D.A.'s going to approve it," Dr. Birmaher continued. "You can't do this in your clinical practice."

Some physicians counter that short-term relief provided by medication can obscure a child's underlying psychological and environmental problems and prevent them from being closely examined. Dr. Rubin, emphasizing that he has prescribed combinations of psychotropics, said, "We're pouring some water on the fire, and my concern is we're never going back to see why the fire got started."

A study published in the September journal of the academy for child psychiatry made one of the first formal attempts to evaluate the short-term addition of Risperdal to stimulants for children like Matthias, who have A.D.H.D. and are severely aggressive. The results after six weeks were mixed: Modest benefits were found in behavior at home but not at school, and there were slightly worse side effects, like weight gain, giving little guidance to clinicians.

It also gave little reassurance to parents like Ms. Kendle, whose patience waiting for solutions can go maddeningly unrewarded.

The Decision

Although Matthias has had some good days at Hidden Valley Elementary School, he struggled during his first three months of first grade. Credit Jim Wilson/The New York Times

Although he pays attention at times and has some good days, he can go from explosive to withdrawn to unreachable. He refuses to do math and word exercises, often putting his head on the desk and ignoring even his teacher's softest encouragement. Most alarming is that during less structured periods, such as recess, he often runs away, disappearing and causing fear for his safety.

Ms. Kendle has heard stories, some from parents in her own community, of children similar to Matthias whose school lives were turned around by the relief that Risperdal can bring. Then she saw a

television commercial in which class-action lawyers asked parents if their son had developed breasts while on the drug, a rare but disturbing side effect.

"Could we try it for a month, and then if you don't see anything bad?" she asked Dr. Diller in his office in late October, her voice trailing off.

"The decision to try it," Dr. Diller said, "doesn't at all rule out stopping it."

Still leery, Ms. Kendle decided to wait. Next week, she will meet with school officials about an Individual Education Plan, which could provide Matthias with more robust assistance — from more one-on-one attention from teachers to full special-education services.

Ms. Kendle hopes that such help can give Matthias a taste of academic success, germinating some self-esteem. Perhaps he really isn't a textbook candidate for Risperdal, but just a child with a chaotic home life whose 6-year-old constitution has not adapted to the increasing scholastic expectations put on young children.

Ms. Kendle's resolve is constantly tested. On a recent Tuesday, she chaperoned a field trip to a pumpkin patch. Ms. Kendle said she overheard a teacher saying: "His mom is on this trip, so she's responsible for chasing him down, not me!"

Matthias threw a fit when his chosen pumpkin was too big to lift. He calmed down, but when all the children gathered to hop on a hayride, he saw a caterpillar in the road and, afraid it might get squished, refused to get on the ride until the creature had crossed to safety. The class waited impatiently.

And then Matthias bolted yet again, running from his mother and the entire group faster than anyone could chase him. He ran and ran and ultimately took roost on a distant fence made of haybales, next to a scarecrow.

By the time Ms. Kendle reached her troubled boy, he was too wired to listen and she too tired to speak. So she climbed up and sat with him silently, on the fence again.