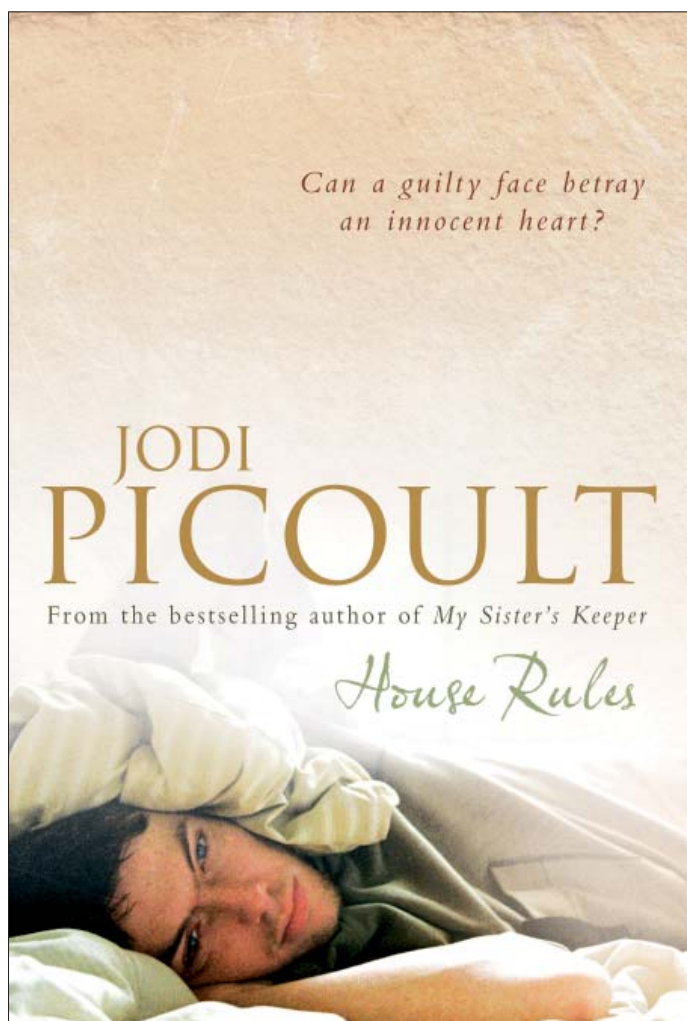


ALLEN & UNWIN



# READING GROUP NOTES

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## About the Book

Jacob Hunt is a teenage boy with Asperger's Syndrome. He's hopeless at reading social cues or expressing himself to others, and like many children with Asperger's, Jacob has an obsessive focus on one subject - in his case, forensic analysis. He's always showing up at crime scenes, thanks to the police scanner he keeps in his room, and telling the cops what they need to do - and he's usually right. But then one day his tutor is found dead, and the police come to question him. Reluctance to make eye contact, stimulatory tics and twitches, inappropriate gestures, all these can look a lot like guilt. Suddenly, Jacob finds himself accused of murder.

House Rules looks at what it means to be different in our society, and at the extremes of love and loyalty a family must call upon to help each other overcome impossible circumstances.

## About the Author

Jodi Picoult is the bestselling author of thirteen novels. She grew up in Long Island and then studied creative writing at Princeton. Following her graduation she had a series of jobs including as a technical writer for a Wall Street brokerage firm, as a copywriter at an ad agency, as an editor at a textbook publisher, and as an 8th grade English teacher - before entering Harvard to pursue a master's in education. She married Tim Van Leer, whom she had known at Princeton, and it was while she was pregnant with her first child that she wrote her first novel, *Songs of the Humpback Whale*.

Jodi and Tim and their three children live in Hanover, New Hampshire with a dog, a rabbit, two Jersey calves, and the occasional Holstein.

### Author, Jodi Picoult, on writing *House Rules*

I remember very well the first time I met my cousin David. He had just been adopted by my aunt and he was the most beautiful baby I'd ever seen - with dark eyes and olive skin and a bright gaze that followed me as I walked around his baby seat. But by the time David was a toddler, we knew that he wasn't an ordinary kid. He was diagnosed on the autism spectrum, and that was the beginning of a comprehensive change in my aunt Nancy's life.

As David became a teenager, his tantrums were harder to control. He was six feet tall and 200 pounds, but profoundly autistic - and the smallest things would set him off in frustration, since he couldn't tell us what he wanted or needed. I remember once when my aunt had to literally sit on David to get him to stop having a meltdown in a store - and the police were called, because to someone who didn't know better, it looked a lot like child abuse. When David turned 21, he moved into a group home with other autistic young adults. During a meltdown, he put his hand through a window - and the caretaker who owned the home called the police to restrain him. Although charges were not pressed, it got me wondering - how would someone autistic be perceived by the law enforcement community? Is a fair trial possible, when you can't communicate well with the rest of the world?

I decided that with the autism rate peaking now - one out of a hundred kids is diagnosed on the spectrum - it was time to write a book that explored this very theme.

Although I had my cousin David as a starting point, I wanted the main character to be able to speak to the reader directly – which meant creating a boy at the high end of the autism spectrum. To this end, I decided that Jacob Hunt would have Asperger’s syndrome – an autism spectrum disorder that’s characterized by problems with social interaction, communication, and imagination, and by restricted and repetitive interests and behaviors. People with AS usually have less trouble speaking and fewer learning disabilities than are usually associated with autism, and they are often of average or above average intelligence. They have difficulty understanding theory of mind – in other words, they can’t put themselves in the shoes of someone else to empathetically understand what these others are feeling or thinking.

Asperger’s Syndrome was first defined by Dr. Hans Asperger in 1944, when he identified symptoms that included a lack of empathy, an inability to form friendships, one-sided conversation, intense absorption in a special interest, and clumsy motor skills in a study of boys who were autistic. Prior to this, autism was thought to be a symptom of schizophrenia. But Dr. Asperger felt that these “little professors” – as he called them – could contribute to community. A lot of Dr. Asperger’s work was lost in a bomb attack during World War II and his findings weren’t translated into English until after his death in 1980. It wasn’t until the 1990s that his findings gained acceptance, and that Asperger’s syndrome became a diagnosis for high-functioning autistics worldwide.

I met with dozens of AS kids, and their parents. Like my fictional Jacob Hunt, the kids were remarkably smart and obsessed by a specific subject. One girl, for example, related everything in her life and personal relationships to episodes of the Disney series “The Suite Life of Zack and Cody.” They are rigidly defined by routine. One boy gets up every day at 5:45 AM – even during summer vacation or snow days – because that’s his routine during the school year. They don’t understand empathy – why on earth would you cry at a sad part in a movie, since the tragedy didn’t happen to you? They completely miss social cues, and have a very different view of conversation. For example, if you are obsessed with dinosaurs and start talking about T-rex and your conversation partner says, “Oh, that’s cool. I’m really into old films” – well, to a kid with AS that’s incredibly rude. To someone with Asperger’s, conversation isn’t a give and take, it’s focused on a single subject of your choice. They are also painfully literal. When one child I met was told by his mother that they were moving to Vermont, where there were beautiful rolling hills, he freaked out – certain that the landscape was going to crush them.

I think the hardest thing about having Asperger’s, though, is that there are times these kids look completely normal. And then at other times, it is blatantly clear that something’s a little different. The parents of AS kids I met with worried about this, and how – in their absence – their children would be able to communicate to others. One mother told me that she’d read AS kids should carry a card in their wallets, stating that they have autism. That way if a police officer approached, the card could be handed over. But this mother also asked, if her son reached for his wallet, would the policeman wait patiently – or assume he was going for a gun, and shoot first?

The most contentious parts of the interviews I did with AS parents, however, involved the vaccine debate in this country. Right now, children receive 38 vaccines against 15 diseases before kindergarten. This is up from 11 shots against 8 diseases, 15 years ago. In other countries with low mortality rates, 18 shots are the average. So what’s the big deal?

Some parents of kids on the autism spectrum believe that there is a link between vaccines and autism. Of the par-

ents I met, about 50% believed in that link, and 50% did not.

The government and the FDA insist vaccines are safe. According to the CDC, if every American child followed the recommended vaccine protocol, 33,000 lives would be saved, 14 million infections prevented, and ten billion dollars would be cut from healthcare costs annually. There has not been a single study conclusively proving a link between vaccines and autism. And 95% of all kids sail through their shots with no side effects.

But a growing number of parents and doctors are asking questions about the safety of vaccines. The debate began with Dr. Andrew Wakefield, the first physician to publish an article in a mainstream medical journal that linked the MMR vaccine, inflammatory bowel disease, and autism. His research was subsequently invalidated. But in spite of this, some people point out that in the 1960s the FDA and the government swore vaccines didn't cause side effects like seizures, autoimmune deficiencies, encephalitis, et cetera. Now that we know they CAN, there are product inserts in every vaccination. The CDC itself admits that there are 30,000 adverse side effects reported each year from shots. Yet perhaps the most compelling reason to buy into this argument came from the parents I interviewed, who showed me home video of their children – perfectly normal toddlers, who, a day or two after receiving a battery of vaccines – were suddenly withdrawn and exhibiting repetitive autistic behaviors – banging their heads against tables, or spinning the wheels of toy trucks over and over.

To these parents, the evidence comes from the University of Washington, where primates were exposed to thimerosal – a type of preservative that was found in children's vaccines prior to 2001. These primates developed an accumulation of mercury in their brains which activated certain brain cells and caused neuroinflammation. Autopsies of autistic people have shown these same activated brain cells and neuroinflammation. And even more remarkably – these primates who were given thimerosal began to stim, to rock, and to avoid eye contact – all hallmarks of autistic behavior.

The proponents of the vaccine/autism link feel that there may be underlying factors that predispose one child to autism versus another – a genetic quirk, a mitochondrial disorder, an immune system sent into overdrive by too many vaccines. To them, when it comes to vaccinations, one size doesn't fit all.

Some of these parents have gone to vaccine court. In March 2008 Hannah Poling's family won a claim saying that her autism was most likely triggered by receiving five shots against nine illnesses in one day. Hannah had mitochondrial disease – a nerve disorder that causes autism-like symptoms and is brought on by viral illness. In Hannah's case, the vaccines did what viruses do: they triggered the reaction. Over the past 20 years, the government has quietly paid out 900 million dollars for vaccine injuries. And in the wake of the Poling verdict, the government has called for new safety studies to see if genetics might make some kids more susceptible to vaccine injury.

Why is the government concerned? Because their biggest fear is a public health risk: these parents might stop vaccinating their children completely, putting other kids at risk for disease. For example, in countries with low vaccination rates, the number of measles cases have risen – a disease we've nearly eradicated in the US.

So if you're a new parent, and you're worried about the controversy surrounding vaccines and autism, what do you do? Well, I'm not a public health professional or even a medical doctor, but the ones who helped me do my research offer these guidelines.

Number 1: Spread out your shots. Look at the MMR vaccine, for example. Before 2008 Merck used to make separate vaccines. It's a live vaccine and is designed to mimic a natural infection and let the immune system fight it off. But this isn't how a child would get the natural infection – measles, mumps and rubella all at once. Theoretically, vaccinating with one live virus at a time might allow their immune systems to handle each disease separately instead of becoming overwhelmed.

Number 2: Delay shots that aren't for immediate disease threats. Hepatitis B and polio aren't threats to babies in the US unless the parent is an intravenous drug user, but they're given to infants so that kids don't wind up missing the protection when they're older.

Number 3: Choose flu vaccines without thimerosal. They are available, if a parent knows to ask for it. The amount of mercury in one shot is miniscule, but scientists don't know how long it stays in a child's brain, or if accumulates over time.

Number 4: Avoid vaccinations if your child is sick. The immune system's already fighting – don't make it work even harder.

Number 5: Be the expert. Do your research. Talk to your pediatrician about the risks and the benefits of each vaccine.

And finally, Number 6: Recognize that there's a way to be cautious, without being radical. I personally would never endorse NOT vaccinating your children; I vaccinated all three of mine. But it is always better to be informed than to be uninformed; and you can alter your child's vaccine schedule in a way that makes sure he'll be protected – and that he won't put any other kids at risk.

The kids I met who have Asperger's are funny, quirky, frustrating, and just as individual as you or I. With the autism rate reaching as high as it has, there's an excellent chance we'll all be touched personally by autism in our lifetimes. I can only hope that HOUSE RULES allows people a glimpse into the world of both a child with Asperger's as well as the effect it has on a family. Who knows? I'd like to believe that if someone had read this years ago, and then had witnessed my cousin's meltdown, my aunt wouldn't have felt shame...but rather, compassion.

## Reviews

'Picoult writes with unassuming brilliance.' - Stephen King

'It's hard to exaggerate how well Picoult writes.' - Financial Times

'Picoult writes with a fine touch, a sharp eye for detail, and a firm grasp of the delicacy and complexity of human relationships.' - Boston Globe

'Picoult has become a master-almost a clairvoyant-at targeting hot issues and writing highly readable page-turners about them..... It is impossible not to be held spellbound by the way she forces us to think, hard, about right and wrong.' - Washington Post

## Discussion Questions

- ☞ Jacob's meltdown give the reader many clues into what Emma's like is like taking care of Jacob. What does it tell us about Emma and her personality?
- ☞ Jacob says, "Why would I want to be friends with kids who are nasty to people like me anyway?" What does this tell us about Jacob?
- ☞ Theo is the younger brother but he has to take care of Jacob. How does Theo handle the conflict of his position in the family? Do you agree that he has it 'worse than Jacob'?
- ☞ Who is a better brother, Jacob or Theo?
- ☞ The evidence points to Mark as a suspect. He claims he's innocent. What does Emma see on the news that changes everything? How would you react?
- ☞ How do you think you might have voted if you were on Jacob's jury?
- ☞ Oliver makes a request for accommodations for Jacob in court. Do they seem fair? The first 5 minutes of the trial show the constant vigilance needed to keep Jacob from having a meltdown and how much Emma does know about her son. Discuss.
- ☞ House Rules is intersected with real-life criminal case studies. What do they bring to the novel?
- ☞ Who are the 'baddies' in House Rules? Who are the 'goodies' and the victims? Who tells the truth? Whose rules are best? Does the book challenge our idea of right and wrong and of legal justice?
- ☞ How would you describe Jacob's ability to feel emotion and relate to people - particularly Emma, Theo and Jess? Is he capable of love, despite his AS?
- ☞ Emma's been a single mom for about 15 years. She doesn't appreciate her ex-husband showing up. Would you? How does she change later?
- ☞ "We've always said that Asperger's isn't a disability ... just a different ability". What did you know about autism and AS before reading House Rules? Did the novel challenge your views on the subject, or on disability more generally?

## Suggested Reading

- ☞ Handle with Care Jodi Picoult
- ☞ Keeping Faith Jodi Picoult
- ☞ Rest of Her Life by Laura Moriarty
- ☞ The Senator's Wife by Sue Miller