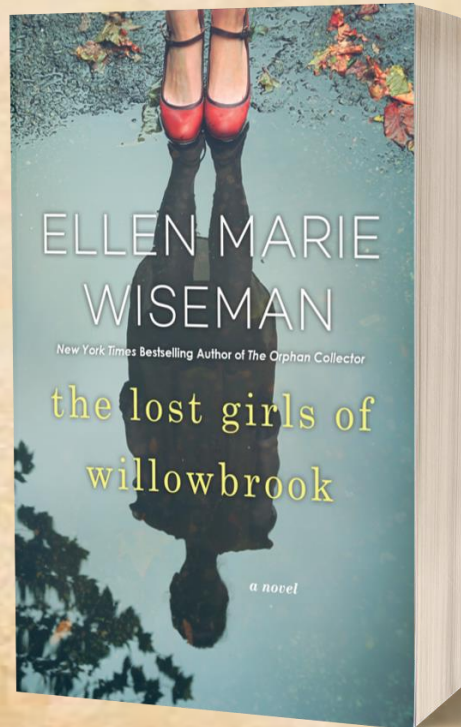


Reading Group Kit

*People still search the woods
for the remains of lost children...*



Girl, Interrupted meets *American Horror Story* in 1970s Staten Island, *The Lost Girls of Willowbrook* plunges readers into the locked wards of Willowbrook State School, the real state-run institution for children with disabilities that became infamous for inflicting horrendous abuse throughout its four decades of operation. It's a harrowing, visceral, yet ultimately inspiring story of social justice and sisterhood, as *New York Times* bestselling author Ellen Marie Wiseman blends fact, fiction, and urban legend for her sixth and most powerful novel to date.

Dear Reader,

On January 6th, 1972, inside a small Staten Island diner, a former physician from Willowbrook State School met secretly with a reporter. After describing the horrible conditions he had been fired for trying to improve at the state-run institution, he handed the reporter a key to one of the buildings.

That reporter was Geraldo Rivera. With that clandestine key, he would lead a film crew unannounced into Building #6 at Willowbrook, where they would capture the appalling abuses, filth, and overcrowding inflicted upon its residents. This year, 2022, marks the 50th anniversary of when Rivera's television exposé shocked the nation with that horrifying, raw footage. It sparked public outrage, a lawsuit was filed against the state of New York, and Willowbrook eventually was shut down. But it took over twenty years.

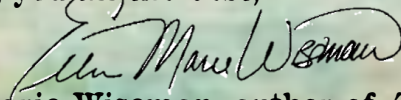
As an author who endeavors to cast light on social injustices of the past within my novels, I've written previously about institutional abuse. Even still, much of what I knew before I began researching the dark history of Willowbrook was based on urban legends and rumors, some of which turned out to be true and made it into this novel in ways that surprised even me.

The more I learned about the institution itself, the more I realized that "life" inside was far more complex than I imagined. And the more my sympathy for those who lived and worked there grew. Far from being a school, Willowbrook was overcrowded, underfunded, and understaffed, the 375-acre idyllic campus with its sweeping lawns and groves of willow trees belying the fact that it was a warehouse for children and adults with and without physical and mental disabilities. Out of public sight and completely closed off, it provided the ideal breeding ground for human abuse and became an underground city with its own hierarchy and society, where employees could buy and sell everything from drugs to jewelry to meat. It also became a hideout for researchers to carry out controversial medical experiments, all of which were funded by the Defense Department.

The Lost Girls of Willowbrook takes place during the early 1970s, a time when the extreme stigma and fear surrounding disabilities pressured parents to give up their children "for the sake of the family." It was a time when words we now recognize as violent and dehumanizing were used to describe the very people most deserving of compassion.

I hope this novel inspires you with Sage's ability to turn heartbreak into a force for good and entertains you with her determination in the face of danger. But most importantly, I hope you are disturbed by the cruel reality of Willowbrook and institutions of its sort. I hope you'll be stirred by how people lived, worked, suffered, and eventually triumphed with the closure of Willowbrook. What happened there should serve as a reminder to us all that we need to be more protective of the most vulnerable among us, and that every human being has the right to learn and grow, and above all, to be treated with kindness, respect, and empathy.

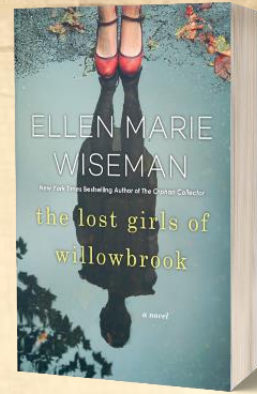
Wishing you all the best,



Ellen Marie Wiseman, author of *The Lost Girls of Willowbrook*
#TheLostGirlsOfWillowbrook

DISCUSSION QUESTIONS

to spark conversation
and enhance your reading of
The Lost Girls of Willowbrook.



1. Located on Staten Island in New York from 1947-1987, Willowbrook State School was a state-run institution for children with intellectual abilities that became known – tragically long before it was finally shut down – for its deplorable abuses, filthy conditions, and overcrowding. An estimated 12,000 residents died at Willowbrook from 1950-1980 due to neglect, violence, lack of nutrition, and medical mismanagement or experimentation. What was your awareness of Willowbrook State School before reading *The Lost Girls of Willowbrook*? Why do you think most people today are unfamiliar with the history of Willowbrook?
2. When Sage discovers her twin sister Rosemary has gone missing from Willowbrook, she takes a bus to the institution to help with the search. She goes alone because her stepfather is cold and indifferent, and she feels like her friends are unreliable. Do you think Sage’s lack of knowledge about the “school” influenced her decision to go there by herself? What would you have done in that situation? Would you have headed to Willowbrook alone?
3. Willowbrook State School first gained infamy after an unannounced visit in 1965 from Senator Robert Kennedy. Despite his vivid descriptions of it as “a snake pit” and his horror over the conditions of the children “living in filth and dirt,” the school continued to operate for another 22 years. In 1972, Geraldo Rivera filmed the Peabody Award-winning expose “Willowbrook: The Last Great Disgrace,” which aired on national television. This documentary brought widespread mainstream awareness of the institution’s abuses, overcrowding, deplorable conditions, and physical and sexual abuse of residents. Shockingly, it wouldn’t be shut down for another 15 years. Were you surprised that Willowbrook was allowed to continue operating for so long? Why do you think it took decades to shut down the institution?
4. How would you react if, after grieving a loved one for years, you found out they were alive but had been committed to an institution like Willowbrook?

5. Willowbrook was grossly overcrowded, underfunded, and understaffed, with one or two attendants per up to 125 residents, and over 200 residents living in houses built for less than 100. While this novel negatively depicts most of the staff members, there were in reality many good, well-meaning people who worked at Willowbrook. There were also wonderful doctors who truly cared for the residents, such as Dr. Mike Wilkins and Dr. William Bronston, who risked their careers and more to improve conditions and bring justice to victims. Do you think the staff and doctors at Willowbrook were just as much victims of the institution as the residents? Why or why not? What do you think were the biggest factors that contributed to the horrible conditions and abuses at Willowbrook?
6. Sage's stepfather says one of the reasons he and her late mother lied about Rosemary being committed to Willowbrook was because her mother wouldn't have been able to show her face in public without people whispering behind her back. At the time, ignorance of mental disabilities meant there was still extreme stigma and fear surrounding it. Since then, there have been some changes in the attitudes and treatment of those with disabilities, although we still have a ways to go. Why do you think that is? When did the change begin? What else needs to be done?
7. When Sage arrives at Willowbrook, the doctors and nurses think she is her missing sister. She tries everything to convince them that she is Rosemary's identical twin but nothing works. Is there anything else she could have tried?
8. Willowbrook State School is mentioned in the 2009 documentary "Cropsey" as reportedly having housed convicted child kidnapper Andre Rand, who previously worked there as an attendant. One of Rand's supposed victims, Jennifer Schweiger, was found buried in a shallow grave behind the grounds of the abandoned institution. Have you ever heard of the legend of Cropsey? Do you know of any urban legends centered in or around the area where you live?
9. How do you think Sage changed over the course of the novel? Which events do you think were most transformative?

10. Sage remembers hearing rumors about scientific experiments being carried out on children at Willowbrook. This rumor turned out to be true. Some of the top virologists in the U.S. used the school as experimental hideout for developing vaccines for hepatitis, measles, mumps, shigellosis, and other diseases, and it was funded by the Defense Department. Other experiments involved hormone treatment, dwarfism, and electro-stimulation, among many others. In 1976, one Willowbrook administrator was quoted as saying he once counted seventy-three separate research projects going on at one time. More recently, vaccinologist Maurice Hilleman has described the hepatitis studies performed at the institution as "the most unethical medical experiments ever performed on children in the United States." Did this surprise you? Have you ever heard of any other medical experiments being carried out in the U.S. on the disenfranchised, impoverished, orphaned, or ill?
11. At one point, Sage learns there are kids without disabilities in Willowbrook who were abandoned by parents and foster homes. Some were left in public places with signs that said, "Take Me to Willowbrook." In real interviews, Willowbrook staff have stated that some well-to-do families got their child into Willowbrook because they couldn't deal with the child's behaviors, even going as far as having IQ scores altered to make them eligible for admittance. And virtually everyone who was examined got in. Why do you think the people in charge let that happen? Why would they commit non-disabled children? Have you heard of hospitals, schools, or centers for "troubled kids" that exist today? Have any of them been accused of neglect or abuse?
12. The idyllic campus of Willowbrook, with its expansive lawns, sweeping stands of trees, and brick buildings, belied the horror that was happening behind its walls. Do you think the citizens of Staten Island knew what was really going on there? Do you think they could have done anything to stop it?
13. This publication of this novel coincides with the 35th anniversary of Willowbrook's long overdue closure on September 17, 1987. Even though Willowbrook no longer exists, do you think the issues it raises surrounding institutional abuse are still relevant today? Are there facilities currently operating that are or could become a "modern day Willowbrook?"

Additional Resources & Further Reading

Books:

- *Public Hostage Public Ransom: Ending Institutional America* by William Bronston, MD
- *A History and Sociology of Willowbrook State School* by David Goode, Darryl Hill, Jean Reiss, and William Bronston
- *American Snake Pit* by Dan Tomasulo
- *The Willowbrook Wars* by David J. Rothman and Sheila M. Rothman

Videos & Online:

- "Willowbrook: The Last Great Disgrace" – Geraldo Rivera's 1972 television exposé www.abc7ny.com/11700456/
- "Cropsey" – Documentary by Joshua Zeman and Barbara Brancaccio
- Penhurst Memorial & Preservation Alliance: www.preservepenhurst.org/

If you'd like to learn more about deinstitutionalization making the future better for people with disabilities, please check out these resources:

People Inc.	www.people-inc.org
Disability Rights Education Fund	www.dredf.org
National Disability Rights Network	www.ndrn.org
International Disability Alliance	www.internationaldisabilityalliance.org
William Bronston, MD	www.PublicHostagePublicRansom.org
PNHP	www.pnhp.org

About the Author



Ellen Marie Wiseman is a *New York Times* bestselling author known for writing novels based on real historical injustices, including *The Orphan Collector*, *What She Left Behind*, *The Plum Tree*, *Coal River*, and *The Life She Was Given*. Her new novel, *The Lost Girls of Willowbrook*, blends fact and fiction as a young woman searching for her missing sister is mistakenly imprisoned at the notorious Willowbrook State School in 1972.

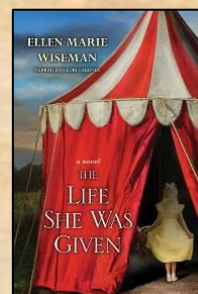
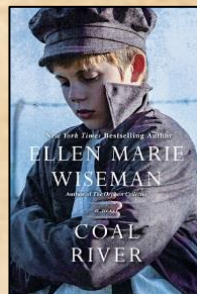
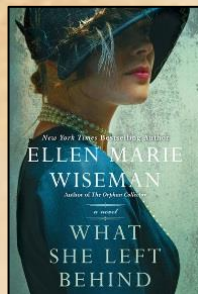
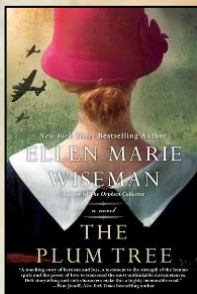
Born and raised in Three Mile Bay, a tiny hamlet in northern New York, Wiseman is a first-generation German American who discovered her love of reading and writing while attending first grade in one of the last one-room schoolhouses in New York State. Since then, her acclaimed novels have been translated into twenty languages and sold more than one million copies in the United States alone. A mother of two, she lives on the shores of Lake Ontario with her husband and a spoiled Shih-tzu named Izzy.

Visit Ellen online at:

www.EllenMarieWiseman.com

Instagram: @EllenMarieWiseman

Facebook: /EllenMarieWisemanAuthor



The next page includes photographs taken by
Dr. William Bronston to document conditions at
Willowbrook State School in the early 1970s.

**These images are disturbing and
should be viewed at your discretion.**

With immense gratitude to
William Bronston, MD
for his permission to share these
photographs, many of which also appear
in his nonfiction book
Public Hostage, Public Ransom.

