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During the Cold War, an alliance between American scientists, pharmaceutical companies, and the US military pushed the medical establishment into ethically fraught territory. Doctors and scientists at prestigious institutions were pressured to produce medical advances to compete with the perceived threats coming from the Soviet Union. In *Against Their Will*, authors Allen Hornblum, Judith Newman, and Gregory Dober reveal the little-known history of unethical and dangerous medical experimentation on children in the United States. Through rare interviews and the personal correspondence of renowned medical investigators, they document how children—both normal and those termed "feebleminded"—from infants to teenagers, became human research subjects in terrifying experiments. They were drafted as "volunteers" to test vaccines, doused with ringworm, subjected to electric shock, and given lobotomies. They were also fed radioactive isotopes and exposed to chemical warfare agents. This groundbreaking book shows how institutional superintendents influenced by eugenics often turned these children over to scientific researchers without a second thought. Based on years of archival work and numerous interviews with both scientific researchers and former test subjects, this is a fascinating and disturbing look at the dark underbelly of American medical history.

## Against Their Will: The Secret History of Medical Experimentation on Children in Cold War America Details

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# **From Reader Review Against Their Will: The Secret History of Medical Experimentation on Children in Cold War America for online ebook**

## **Jillisa says**

This is a book that will make you think. What is the definition of human? When does the principle of the "greater good" prevail and who defines the term? What price are we willing to pay for the advancement of modern science and technology? The authors did an excellent job in this book exploring the motivations that drove researchers to use the methods they did and the bigger picture of a society that turned a blind eye. The book is divided into logical chapters by the types of experiments done and each chapter contains at least one personal story of a survivor. Not only were these children who were being used, many of them were children with mental disabilities and the experiments that were performed seem, in many cases, illogical. (Of course if you feed someone infected feces they're going to get sick!) The information presented was eye opening to say the least, especially the epilogue where the authors revealed that the same type of medical experiments are still taking place... just outside of the now regulated U.S.

In some areas I felt the book was repetitive, using the same doctors and stories over and over again. If the problem was really so widespread (and from this book I believe it was) then there should be more stories that could be used. Also, the authors use the terms of the time to refer to various mental and/or physical disabilities but do not always provide a translation into today's term. Therefore, I was 3/4 of the way through the book before I knew that "mongoloid dwarfism" is now known as Down's Syndrome. All of that is minor. However, the one thing that would have made this book really great would have been more details on the individuals it covers. What were the long term effects on those who underwent the experiments? How, specifically, was the course of each one's life changed? Have the researchers and doctors changed their minds and attempted to make restitution? Have any of them faced charges? Many individuals' stories were shared in this book but I can't say the book really helped me feel a connection to any of them that truly made my heart ache and my blood boil.

Against Their Will opened my eyes and gave me facts to consider but a book with such subject material should be able to move one's heart and that was lacking.

I received this book from the publisher in a random drawing on Goodreads. My positive review was not a condition of receiving this book.

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## **Pat Thelander says**

For me - a very difficult read due to a personal level. It was rather intense, supporting many things I had suspected and revealed much more. Mixed emotions - damned if you do, damned if you don't.

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## **Donna says**

Don't read this book if you are sensitive to cruelty and ignorance.

It documents the experimentation on and medical treatment of people who had no rights or were unaware of their rights: prisoners, children in mental institutions, orphans, the poor and even trusting gullible educated adults.

The book includes testing of vaccines and medicines; radiation experiments; lobotomies, electroshock therapy and LSD "treatment" for mentally ill and/or mentally "disabled" people; use of non-approved drugs for birth control; involuntary sterilization; forced child labor in institutions; sexual and physical abuse; lying and misrepresentation to illiterate parents; all on members of the public who had nobody to protect them. Ironically this was encouraged at the same time as the Nuremberg trials were denouncing this type of medical experimentation.

This is not a book easily read. It documents the infants, children and adults who died from these experimental drug and electric treatments. It describes the horrible pain and side effects endured even after the treatments for which no pain killers were administered, children holding their hands over their eyes day and night, shrieking from the pain caused by substances administered to their eyes. It describes the long term damage to the brain, personality and memory as a result of lobotomies and electroshock therapy.

The book describes the twisted thinking of scientists who felt that "feeble-minded" and physically disabled people, called idiots, morons and gargoyles, etc. would at last have the opportunity to have meaning in their lives by contributing to the knowledge of science, even if they were damaged or killed by the experiments. It describes the eugenics movement and how people were sterilized without their knowledge because they were told that the world did not want them producing more "like them". It describes the, well, the word "stupidity" comes to mind here, even though I am talking about scientists.... the stupidity of scientists who thought that their patients were "healed" because they were sitting quietly unable to communicate after lobotomies and shock treatments.

It details the lack of controls over drugs like thalidomide and the dishonest and/or sloppy research encouraged by the source of funds...

Sadly the book ends by describing how we must become more aware... but it deals with this matter historically. It does not discuss current similar problems such as vaccines, the use of psychotic drugs in school-age children, the use of mercury in fillings (which are called silver or amalgam despite having a 50% mercury content, etc. I do not think the situation has changed much. Some hospitals still use experimental drugs without the knowledge or consent of their patients; some governments and drug manufacturers misrepresent the ingredients and side effects of vaccines, some university researchers are paid by a company to investigate whether their new product will negatively affect the current industry (influencing the outcome of the "independent" study); some military investigations of deaths during training still request the coroner to find that the military was not at fault...

I think the problems detailed in this book still exist in different forms.

Yes, we should be aware. We should be wise. We should be proactive. And we should not be trusting, believing that because we have discovered this about our past that it will not happen again.

This book is thorough, detailed and well researched. But it needs to be brought to the present. It is easier to write a book about historical events where the "enemies" are all dead than to write a book about present companies and politicians who are doing the same thing today. They can fight back.

I hope there is a "sequel" to this book.

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### **Susan Bazzett-Griffith says**

Three stars-- possibly 3.5. There is a lot to like about this book-- the research is in depth and fascinating, the personal stories horrifying, and the lengths gone to cover up what occurred in medical research over the last century very disturbing. That said, the title is misleading to a degree. The book is much larger in scope than just the Cold War era, with history delved into as far back as the late 19th century. The history is important, and interesting to read; however, it takes away from the focus that I wanted to read about which was the mid 20th century, specifically. I believe the book would have been stronger and more moving if Hornblum had gone into further detail and follow up on more of the test subjects later in life, but perhaps that information wasn't traceable. At any rate, if you're interested in the darker side of scientific achievement, the eugenics movement, radiation experiments and the like, you'll enjoy this book. For as scientific as the research is, it is very readable material.

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### **Marian says**

High-impact in its catalog of dehumanizing medical research that exploited institutionalized, often disabled children for almost a century (as far as documentation presented here), and with a valuable list of source notes. The writing leaves a lot to be desired, some experiments are vaguely described, the authors often lapse into stigmatizing language of the sort they ostensibly deplore, and the higher-level arguments/analyses are weak or superficial -- therefore it earns a place in my "painful" category. Nevertheless, it's highly valuable for the content overall, as well as the list of source material.

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### **Sandy Grant says**

What a disappointment this book was. Great concept, very poor execution. It had very little to do with the cold war.

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### **Meredith says**

There's a lot of really interesting information in this book, and it's a history that should be more well known. The writing in general is good, but the organization is bad and the writing is sometimes repetitive. Each experiment is also covered quite briefly, so be prepared to look for other books if particular issues grab you.

The title/cover is also a bit sensationalistic given how few experiments in the book actually had anything to do with the Cold War, and how much of it was devoted to other time periods entirely. It is more like the shortest book it was possible to write on the general history of child experimentation in the 20th century. In the later chapters many of the stories aren't actually experiments, just questionable practices doctors embraced with vigor regardless of how little research had been done.

A frequent refrain is "Doctors in the US didn't pay any attention to the Nuremberg code at all." There's a chapter about WWII and the Nuremberg code but that line is still repeated frequently (numerous times in a

single chapter) in reference to individual doctors/experiments. There are some other specific ideas that are over-repeated as well (such as researchers specifically choosing devalued populations vs college prep schools).

The individual sections on vaccine research, radiation research, etc... aren't organized chronologically and sometimes aren't organized in a logical way at all. There's also a slight tendency to leave out dates when something prior to 1945 is being talked about it, or sometimes the date is mentioned towards the end of the story that's being related, which is always frustrating, but especially so in a book that jumps around so much and mentions so many different experiments.

Again, lots of interesting information here, but it could have been presented so much more effectively and with a less misleading title.

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### **Angela says**

A very interesting look at the experiments performed in the United States in the pursuit of vaccines, cures, studies, and race to invent/prevent possible biological weapons. Some truly horrible things have been done to our orphans, psychiatric patients, prisoners and unwitting participants. What do we do? Testing must be done, but never on those who are unable to make choices for themselves. Most of the testing has moved overseas where FDA and regulations do not reach. It is a sad business.

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### **David says**

One of the most disturbing books I have ever read. I knew about unethical psychological studies, the Tuskegee airmen 'experiments' and the forced sterilization programs targeting the poor in the south, but I had no idea about the experiments done on institutionalized children, pregnant mothers, radiation studies on infants, cruel studies on those with cerebral palsy... The litany of horrors presented here are well researched and thoroughly horrifying; on par with Japan's Project 731 and Nazi medical experiments, which were of course viewed as the horrors they were. All the while, we were doing experiments just as horrific on children, infants, mothers, the illiterate, and those deemed by the eugenicist movement as being "defectives," euphemistically called "research material." A sordid chapter in American history that should be required reading, instead of hidden away so as to detract from our jingoistic 'history' taught in schools. I docked it a star because quite a bit of the research happened before the Cold War, as the title suggests, but a good deal did take place during that era, which is disturbing enough in itself.

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### **Joan says**

Not exactly Cold War era. Not exactly constructed concisely in a coherent or unified way. That being said, good research, good documentation and gives a peek into some of the lives affected and effected by experimentation, government run medical programs and our history as people in the health field. My heart goes out to those lives in whom I have benefitted from vaccinations, medical breakthroughs and practices. It is from their sacrifice of quality of life, or sacrifice of life without permission or knowledge that we have gained perspective. Belatedly, they should be honored and respected and thanked.

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## **Donna says**

A very interesting book. Lots of things I never knew.

I understand the need for human subjects when it comes to medical testing, and the breakthroughs that were made because of some of this testing were historic, but the way it was conducted without permissions from relatives or parents or guardians of the children and adults institutionalized at the time is unforgivable. Children and adults were often institutionalized because of the stigma attached to having a "feebleminded" or "problem" child in the family. They buried them away in institutions, thinking it would be best for them, when many of them were just what we would call autistic today. As a result these children were experimented on without their knowledge and actively lied to about being in a "Science club." And if they resisted they were punished.

The book discusses drug experiments including vaccination experiments for polio and measles, (We think Salk is a hero, in reality he experimented on children without parental consent and children died for his medical contributions.) radiation experiments, such as feeding kids oatmeal laced with radioactive isotopes, LSD experiments, lobotomy experiments, and drug experiments on poor uneducated women including forced birth control (Depo-Provera and Norplant) and sterilization. Poor uneducated women who were pregnant were given thalidomide and DES and radiation all under the guise of healthcare to see what affect it would have on their offspring.

This all was taking place not just back in the 40's and 50's but as recently as the 1970's and 80's.

I grew up visiting the Wrentham State school for events, fairs, and fundraising things. Nobody knew about some of the horrible things happening there at the time. After reading this I am not suprized at the fervor of some people trying to close the institutions in question.

After reading this book, I am left with ... How could anyone let this happen, be actively involved with such atrocities? In many ways it's a disturbing look at what children were put though all in the name of science.

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## **dejah\_thoris says**

Sadly, a terrible but necessary subject to discuss in America's recent past. I naively thought most of these atrocities happened in Europe during the Nazi regime, but unfortunately that is not the case. In fact, despite the creation and knowledge of the Nuremberg Code, many physicians felt that such restrictions did not apply to them or their research. Granted, the Cold War mentality is significantly to blame for many of these failures, as is an under-appreciation of handicapped human life, but many of the lives ruined by these experiments on institutionalized children could have been saved had ANYONE in the medical profession spoken up against their abuse. (Or supported those children who tried desperately to escape.) Tragic beyond measure, this book will enlighten you to another dark chapter of America's past. Fortunately, personal accounts are sparse, allowing the reader to detach from the horror just enough to process its impact without being truly overwhelmed.

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## **Aggie says**

I wish everyone would read this. The true, sad history of human experimentation and eugenics - where? Nazi

Germany, right? Nope... and if you think babies and developing nations are a much better substitute for asylums and orphanages or that doctors don't succumb to paternalism anymore you don't need to read it- you're part of the problem.

A very important, well-sourced book with the stories of real doctors and the lengths they went/go to in the name of science, including interviews with some who survived the and cases of real patients/victims who didn't.

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## **H Wesselius says**

A large amount of information is collected and presented yet there is no coherent structure to the book. The material lends itself to numerous topics; evolution of human rights, the history of modern medicine, the cold war, etc yet there is very little of this to be seen here and instead you have a recitation.

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## **Yaarsse says**

This book would rate 3 1/2 stars, but I'm giving an extra one for the excellent (and extensive) bibliography and footnotes.

Since I've delved – more deeply than is wise if one doesn't want to lose all faith in society – into the history of US eugenics programs and since I already knew about the dubious legacy of Drs. Freeman, Watts, and Bender from college psych classes, I didn't expect to find anything in this book to shock me. I was wrong. One has to wonder what sort of person can balance the cognitive dissonance of claiming to work for "the good of mankind" while they infect infants' eyes with TB bacteria or give children daily doses of LSD for months on end just "to see what happens."

Perhaps the most disturbing things about this sordid history is how orphans and asylum inmates were widely described by researchers as throwaway people and how there was so little resistance from those charged with the care of children and invalids. These "undesirables" were damaged goods, merely collateral damage of someone's research goal.

The authors set an ambitious target. I think they fell short of the goal. While a good overview, the content only skims the surface of this complicated subject and does little to inform about the aftermath of these events. The lack of detail sometimes made chapters feel like PowerPoint presentations. There's so little information on each experiment and so much of the talking points are repetitious that the focus is lost.

In my opinion, the most obvious problem is that the title is misleading: it sets a false expectation. The sensationalized title and cover graphics tell us we're going to be reading about a very specific time period, but background material (and the fallout of the stories) fall far outside the range of the Cold War years. The authors' attempt to tie the research activities directly to the Cold War feels like they are trying to force a point rather than prove one. They might have been more successful to present the convergence of medicine, money, and military using the same timeline drawn in the book *The Great Influenza*, which set the foundation and pivot point of the research era closer to WWI and WWII.

The other problem with the emphasis on the Cold War era is one of context. It mistakenly assumes all



readers will have a firm background in Cold War society and politics. The Cold War is generally said to have been from 1947 to 1991. I am skeptical about those dates as I was well into adulthood in 1991 and don't remember people concerned on a daily basis about "the Communist Menace," not like in the 60s when we were practicing "duck and cover" and Saturday air raid drills. By the 1980s, the Cold War was mostly a Reagan political talking point and the backyard bunkers were forgotten. Nonetheless, the average 24-year old today, born circa 1991, is as far removed from experiences of the Cold War era as the 24-year old me was removed from the Great Depression. Sure, I've heard of it, but it was a generation (plus some) back in time, something about which I know facts, but lacked personal experience. If you think I'm wrong, go find a 30-year old and ask him or her to explain Vietnam War era society and politics to you. (Then again, I don't think any of us understand the Vietnam War.)

What the authors seem to attempt with the constant mentions of the Cold War and Nuremberg Code is show the hypocrisy of the United States' "do as we say, not as we do" posturing. The Allies tried to hold Nazi doctors accountable for ethics violations and experimentation on concentration camp inmates; however, before, during, and after the Nuremberg Code was drafted, doctors in the United States committed very similar atrocities with no ethical concerns or repercussions. The authors assume that briefly outlining what the Nuremberg Code says would carry the weight of their thesis. Nuremberg was 1947-1948, so even further removed in time--and thus in current readers' knowledge--than the Cold War itself. I'm betting if I went out on the street and asked ten random people what the Nuremberg Trials were, nine of the responses would be either wrong or "I have no idea."

What most people—even the ones who know what the Nuremberg Code is--don't realize is that the Nuremberg Code had no legal force behind it. Its contents weren't adopted into law anywhere until decades after it was drafted. Some of the doctors quoted in the book admitted they paid no attention to the trial or the code and didn't know much about it. It wasn't on their radar.

The authors also fail to mention the results of the Nuremberg Doctors Trials. Of the 23 doctors on trial, seven were put to death, seven were acquitted, and the rest were sentenced jail time. Of those sentenced jail time, most sentences were commuted to less than 15 years. Several defendants went back to practicing medicine. Maybe more than a slap on the wrist, but the punishment hardly fit the magnitude of the crimes. Drs. Becker-Freyseng, Ruff, Schafer, and Blome, among others, were then recruited by the United States government for programs peripheral to Operation Paperclip. They were involved with research in chemical warfare, space medicine, and aviation medicine. Operation Paperclip was really all about the US being so scared shitless of "the Russian threat" that we were willing to overlook those little indiscretion of concentration camp atrocities and nasty medical experimentation as long as it meant the brainiacs who committed them were now on "our" side. Including that bit of trivia might have bolstered the authors' point that giving poor, illiterate, pregnant women plutonium cocktails without their knowledge and consent was definitely a Cold War thing. They would have needed to make the book a lot longer to make that point perhaps...which would have been fine.

Some other things I wish had been addressed include these: What are the modern terms for the archaic medical conditions discussed (e.g. Mongoloidism versus Down's Syndrome)? What is the current theory about whether childhood schizophrenia is a legitimate diagnosis? Where did the research funding come from? Did the institutions (prisons, asylums) receive any of the funding? Who was financially benefiting *personally* from these arrangements and the results, and in what manner? What was the process for a child with parents (not an orphan) to be institutionalized? (e.g. How much power did social workers and courts have in making a child a ward of the state?) At what point were laws passed addressing unethical practices, and what would have been the procedure for reporting and investigating claims of abuse? What would the consequences (if any) of breaking said laws? Have any of the victims been recompensed in any way for the

long-term effects of these experiments?

This book would make good elective reading choice for a US history or history of psychology class, but it could have been so much more.

As an aside, one statement that caught my eye was that Senator Edward Kennedy was the Chair of the Health and Scientific Research Subcommittee when some of these abuses were investigated. Considering Walter Freeman (aka the Henry Ford of Icepick Lobotomies) and partner James Watts performed the lobotomy that rendered Rosemary Kennedy an imbecile, no doubt Senator Kennedy had a few colorful thoughts about doctors who throw ethics to the wind when experimenting on intellectually challenged children. Perhaps the authors felt that including that tidbit would weaken their argument about the victims of these atrocious wild-west experiments being defenseless. Frankly, I think it makes the argument stronger. The Kennedys were educated, wealthy, and powerful; yet even they couldn't keep their daughter from being the victim of fad medical practices or from falling into the hands of an egomaniac hell-bent on making a name for himself. If a Kennedy child was treated thus, how could an orphan or institutionalized child of illiterate or impoverished parents hope to fare any better?

Oh, and heads up to the easily nauseated: it's really not a good idea to drink chocolate milk while reading the chapters on radiation and dysentery experiments. And if you are squeamish about the words "icepick" and "eyeball" being in the same sentence, consider yourself forewarned about the lobotomy chapter.

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