

New York's HIV experiment

By Jamie Doran
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HIV positive children and their loved ones have few rights if they choose to battle with social work authorities in New York City.

Jacklyn Hoerger's job was to treat children with HIV at a New York children's home.

But nobody had told her that the drugs she was administering were experimental and highly toxic.

"We were told that if they were vomiting, if they lost their ability to walk, if they were having diarrhoea, if they were dying, then all of this was because of their HIV infection."

In fact it was the drugs that were making the children ill and the children had been enrolled on the secret trials without their relatives' or guardians' knowledge.

As Jacklyn would later discover, those who tried to take the children off the drugs risked losing them into care.

The BBC asked the Alliance for Human Research Protection about their view on the drug trials.

GUINEA PIG KIDS

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Spokesperson Vera Sherav said: "They tested these highly experimental drugs. Why didn't they provide the children with the current best treatment? That's the question we have.

"Why did they expose them to risk and pain, when they were helpless?"

"Would they have done those experiments with their own children? I doubt it."

Power and authority

When I first heard the story of the "guinea pig kids", I instinctively refused to believe that it could be happening in any civilised country, particularly the United States, where the propensity for legal action normally ensures a high level of protection.

But that, as I was to discover, was central to the choice of location and subjects, because to be free in New York City, you need money.

I've had many ACS case workers tell me: 'We're ACS, we can do whatever we want'

David Lansner, family lawyer

Over 23,000 of the city's children are either in foster care or independent homes run mostly by religious organisations on behalf of the local authorities and almost 99% are black or hispanic.

Some of these kids come from "crack" mothers and have been infected with the HIV virus. For over a decade, this became the target group for experimentation involving cocktails of toxic drugs.

Central to this story is the city's child welfare department, the Administration for Children's Services (ACS).

The ACS, as it is known, was granted far-reaching powers in the 1990s by then-Republican Mayor Rudi Giuliani, after a particularly horrific child killing.

Within the shortest of periods, literally thousands of children were being rounded up and placed in foster care.

"They're essentially out of control," said family lawyer David Lansner. "I've had many ACS case workers tell me: 'We're ACS, we can do whatever we want' and they usually get away with it."

Having taken children into care, the ACS was now, effectively, their parent and could do just about anything it wished with them.

'Serious side-effects'

One of the homes to which HIV positive children were taken was the Incarnation Children's Center, a large, expensively refurbished red-bricked building set back from the sidewalk in a busy Harlem street.

It is owned by the Catholic church and when we attempted to talk to officials at Incarnation we were referred to an equally expensive Manhattan public relations company, which then refused to comment on activities within the home.

Hardly surprising, when we already knew that highly controversial and secretive drug experiments had been conducted on orphans and foster children as young as three months old.

We asked Dr David Rasnick, visiting scholar at the University of Berkeley, for his opinion on some of the experiments.

He said: "We're talking about serious, serious side-effects. These children are going to be absolutely miserable. They're going to have cramps, diarrhoea and their joints are going to swell up. They're going to roll around the ground and you can't touch them."

He went on to describe some of the drugs - supplied by major drug manufacturers including Glaxo SmithKline - as "lethal".

When approached by the BBC, Glaxo SmithKline said such trials must have stringent standards and be conducted strictly in accordance with local regulations.

Battle of wills

At Incarnation, if a child refused to take the medicines offered, he or she was force-fed through a peg-tube inserted into the stomach.

Critics of the trials say children should have been volunteered to test drugs by their parents.

When Jacklyn Hoerger later fostered two children from the home where she used to work with a view to adopting them, she discovered just how powerful the ACS was.

"It was a Saturday morning and they had come a few times unannounced," she said. "So when I opened the door I invited them in and they said that this wasn't a happy visit. At that point they told me that they were taking the children away. I was in shock."

Jacklyn, a trained paediatric nurse, had taken the fatal step of taking the children off the drugs, which had resulted in an immediate boost to their health and happiness.

As a result she was branded a child abuser in court. She has not been allowed to see the children since.

In the film *Guinea Pig Kids*, we follow Jacklyn's story and that of other parents or guardians who fear for the lives of their loved ones.

We talk to a child who spent years on drugs programmes which made them and their friends ill, and we discover that Incarnation is not an isolated case. The experiments continue to be carried out on the poor children of New York City.

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