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With this in mind, running experimental drug studies on

children seems especially dangerous and thus horrendous,

yet it is still a common occurrence even in modern society.

In her Nov. 30, 2004 BBC News article "Guinea Pig Kids"

and her subsequent documentary of the same name,

Jamie Doran reveals New York City's Administration for

Children's Services' (ACS) little-known practice of using

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AIDS drugs. For his documentary and article, Doran interviewed Jacklyn Hoerger, a pediatric nurse who worked at the Catholic Church-run Incarnation Children's Home in Harlem. Hoerger maintains that social work authorities never told her that the drugs she and the other Incarnation employees were administering the orphans and foster care children were experimental. "We were told that if they were vomiting, if they lost their ability to walk, if they were having diarrhea, if they were dying, then all of this was because of their HIV infection," she said to BBC.

In reality, **these symptoms were due to the experimental drugs that the workers were giving them**. When BBC asked him his opinion on the experimental drug studies done on New York City's orphans and foster children, University of Berkeley visiting scholar Dr. David Rasnick explained, "We're talking about serious, serious side effects. These children are going to be absolutely miserable. They're going to have cramps, diarrhea and their joints are going to swell up. They're going to roll around the ground and you can't touch them." According to BBC reporter Doran, Dr. Rasnick went on to call the experimental AIDS drugs that were given to the children "lethal." If children refused to take them by mouth, workers at Incarnation force-fed them the drugs through feeding tubes inserted into their stomachs.

It's no doubt that these HIV-positive and AIDS symptomatic children needed medication. The question is why were they given *experimental* drugs, rather than the same medications that a child living in an expensive brownstone on the Upper East Side would have received? In the words of Alliance for Human Research Protection spokesperson Vera Sherav: "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." Furthermore -- when you consider the fact that, according to the BBC article, 99 percent of the children in New York City children's homes are either African American or Hispanic -- issues of race and prejudice also come into play.

Hoerger told BBC that she didn't realize what was going on until she later took two children from Incarnation home as foster children. As a trained pediatric nurse, she decided to take the two children she was caring for in her home off the medications given to them while at Incarnation. This resulted in "an immediate boost to their health and happiness," according to BBC. However, soon after her decision, ACS came to her home and took the children out of her care. She was then labeled a child abuser in court and, after that, she never saw the children again.

Performing medical experiments on children is a serious accusation. Realizing this, while working on his documentary and article, Doran went to Incarnation for its side of the story, but it only referred him to its public relations firm. The expensive Manhattan firm told him that it didn't give comments about what goes on inside the home. In light of these accusations, former ACS Commissioner John B. Mattingly ordered a comprehensive review of all ACS records. By early April, based on the records they had examined, ACS staff members revealed just how common the experimentation Hoerger described at Incarnation was throughout the city:

- Between 1988 and 2001, 465 foster care children and orphans were used in experimental AIDS drug trials.
- Most of these children participated before 1996.
- The majority of HIV-positive children living in New York City were diagnosed from the mid-1980s through the mid-1990s.
- The highest number of AIDS-related deaths among New York City children happened from 1990 to 1995.
- The 465 children used in the studies were in approximately two dozen different independent agencies operating under contract to ACS.

Then, on Apr. 22, 2005, ACS sent out a press release stating that it had "contracted with the Vera Institute of Justice to conduct an independent review of ACS policy and practice regarding the enrollment of HIV-positive children in foster care in clinical drug trials during the late 1980s and 1990s." It also asserted: "The last child to enter an HIV-related clinical trial while in foster care did so in 2001. There are no ongoing HIV-related clinical trials involving children in foster care in New York City." This directly contradicts the conclusion Doran writes in his 2004 article: "The experiments continue to be carried out on the poor children of New York City."

ACS maintains that it ordered the studies with the best interest of HIV-positive children in mind. "The purpose of the drug trials was to develop effective treatments for pediatric AIDS, at a time when there were no known, FDA-approved medications available to treat children with the disease, and many children were dying," reads the press release. As proof of the gravity of the AIDS crisis ACS faced when conducting the trials, the press release cites the following figures from the New York City Department of Health and Mental Hygiene:

- Out of the 13,927 HIV-positive children under age 13 nationwide prior to 2003 (according to CDC estimates), the percentage of HIV-positive children in New York City was "the highest by far of any jurisdiction in the country."
- From 1979 through 2003, 3,634 children living in New York City and under the age of 13 were HIV positive.

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Even though ACS believes that its decision to give the experimental AIDS drugs to the 465 foster children and orphans was not wrong, it is nevertheless ordering the Vera Institute to conduct the independent study, so as to assure the public and the media. As Commissioner Mattingly explained, "We are taking this step because, while we believe that the policies in place at the time reflected good practice, we acknowledge the need for transparency in all of our dealings with the public. In order for us to be effective in our mission to protect New York City's children, we must have a sense of mutual trust with those families we seek to serve." According to the press release, the Vera Institute "will research ACS policies and procedures to ensure that HIV-positive children and children with AIDS who were in the care of ACS were appropriately enrolled in the correct clinical drug trials." This includes finding out whether:

- ACS obtained consent from the children's parents or other guardians before enrolling them in the experimental drug studies.
- The children enrolled in the trials met the medical criteria to do so.
- ACS adequately and properly monitored the children who were enrolled.
- Enrollment was "appropriate based on sound medical knowledge at the time."

As of an Oct. 5, 2005 update to its web site regarding the analysis, the Vera Institute still had not completed its investigation. It writes that it is "assembling an advisory board of medical, child welfare, legal, and community experts to review our findings and assure the public of the independence of our research." Meanwhile, in its description of the project, the Vera Institute acknowledges both sides of the controversy:

"Opponents of involving foster children in clinical trials -- where the risks and benefits are often unknown -- worry that this highly vulnerable population may be too-easily neglected or even exploited. When it comes to children of color, in particular, they point to historic examples where the health care system has acted in discriminatory and prejudicial ways.

"On the other hand, those who favor including foster children in clinical trials argue that enrollment can provide high quality care and cutting-edge medicine to children who otherwise would receive only routine medical services. In this view, excluding foster children unfairly bars them from the best the medical profession has to offer."

It will be very interesting to see the Vera Institute's findings -- which are, according to the Institute itself -- "part of Vera's mission to improve government systems." "We hope that the information we provide will contribute to the public debate that will help shape future policies regarding clinical trials and children in government custody," the site reads. On a national level, between 12,000 and 13,000 children under the age of 13 have participated in National Institutes of Health-sponsored AIDS drug trials from 1986 to 2005.

Even though the Vera Institute's findings are not yet complete, the Environmental Protection Agency's (EPA) Apr. 8, 2005 cancellation of its Children's Health Environmental Exposure Research Study (CHEERS) shows what a combination of intense opposition from environmental and public health groups (as well as a little help from Congress) can do to end experimentation on poverty-stricken children.

Child medical experiments at the EPA

In October 2005, the American Chemistry Council gave the EPA \$2.1 million to study how children ranging from infancy to three years old ingest, inhale or absorb chemicals. Like IG Farben was for the German pharmaceutical companies of Nazi Germany, the American Chemistry Council acts much like a front group for chemical industry bigwigs like Bayer (which was incidentally also a member of IG Farben), BP, Chevron, Dow, DuPont, Exxon, Honeywell, 3M, Monsanto and Procter & Gamble. Studies have already proven that the chemicals made by these companies have *long-term* effects on children and adults. A short, two-year study like CHEERS would of course fail to reveal these long-term effects and the American Chemistry Council could then publicize these findings as "proof" that its chemicals were safe.

This represents an ethical problem in itself, but the demographic of the proposed child test subjects worsen the issue, especially in light of the use of foster children (the majority of which were African-American and Hispanic) by both the New York City ACS and the Tuskegee Syphilis Study. According to the EPA's original study proposal, portions of which were reprinted by the Organic Consumers Association, test subjects would be chosen from six health clinics in Duvall County, Fla. Given the characteristics of these health centers, page 23 of the study proposal itself highlights that minority children from low-income families would be the likely test subjects: "Although all Duval County citizens are eligible to use the [health care] centers, they primarily serve individuals with lower incomes. In the year 2000, seventy five percent of the users of the clinics for pregnancy issues were at or below the poverty level ... The percentage of births to individuals classified as black in the U.S. Census is higher at these three hospitals than for the County as a whole."

In fact, the health care centers report that 51 percent of their births are to non-Caucasian mothers, and that 62

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Human medical experimentation on children: The exploitation of poor children by Big Pharma (part two)

percent of mothers received only elementary school or secondary school educations. If the EPA were to have proceeded with CHEERS, children born to these health care centers would have been used as human guinea pigs simply because they belong to minority groups and poverty-stricken families. In return for allowing their children to be exposed to toxic chemicals, the families were to have received \$970, a free video camera, a T-shirt and a framed certificate of appreciation.

Fortunately, the EPA decided not to go through with CHEERS, once U.S. Senators Bill Nelson (D-Fla.) and Barbara Boxer (D-Calif.) decided to put their feet down and block President Bush's nomination of Stephen Johnson for head of the EPA. In his Apr. 8 statement, Johnson reversed the EPA's earlier decision to await a report from an independent science advisory panel before making a decision about CHEERS. He explained his decision as being a result of public and media "misrepresentations" of the study:

"Last fall, in light of questions about the study design, I directed that all work on the study stop immediately and requested an independent review. Since that time, many misrepresentations about the study have been made. EPA senior scientists have briefed me on the impact these misrepresentations have had on the ability to proceed with the study.

"I have concluded that the study cannot go forward, regardless of the outcome of the independent review. EPA must conduct quality, credible research in an atmosphere absent of gross misrepresentation and controversy."

Boxer, who says that she will continue to oppose testing toxins on humans, called CHEERS an "immoral program to test pesticides on children" and "a reprehensible idea that never should have made it out of the boardroom" in her statement to the Associated Press following Johnson's decision. Luckily, unlike Tuskegee, the study was stopped before anyone got hurt.

This story continues in part three.

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