

Inside Incarnation

By Liam Scheff

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Mimi Pascual gave the children drugs every day and every night, on schedule, as the doctors ordered. She shook the children awake and popped the pills into their mouths, or squirted a syringe full of ground pill and water to the back of their throats. She and the other child-care workers made the rounds: midnight, 3 a.m., 5 a.m. Some kids took the pills by mouth, some through nasal tubes, and some through tubes jutting out of their stomachs. The children didn't like the drugs. They'd wake up vomiting or with bad diarrhea. But Mimi and the workers at Incarnation Children's Center had to follow the regimen, or they'd be fired. "The drugs had side effects, everybody knew that," said Mimi. But the workers were told the drugs were saving the children's lives. After a young girl who had just gone on the drugs had a stroke and then quickly died, and another young boy who was put on thalidomide wasted away on a respirator, Mimi stopped believing that the drugs were just saving lives. She believed they were killing the children too.

Mimi Pascual worked at Incarnation Children's Center for eight years over a nearly 10-year period, taking care of the abandoned HIV-positive children of drug-addicted mothers in New York City's Washington Heights neighborhood. She started at ICC in 1995, when she was just 17. Mimi was one of two dozen neighborhood women from Washington Heights, Harlem and Inwood Heights who were hired by the Catholic nuns who ran the orphanage for abandoned babies.

Like Mimi, the vast majority were originally from the Dominican Republic, and had no medical background. Some spoke only negligible English. But they were all mothers, aunts, big sisters and grandmothers themselves, used to taking care of large families on a shoestring, to keeping life together under great stress, and, as Mimi tells me, used to "cleaning ass," a skill that was useful at ICC.

Hired as a child-care worker, she soon found herself a surrogate mother to the children, changing them, feeding them, holding and hugging them—and drugging them.

"At first they were little babies," Mimi told me. "We changed their diapers and cleaned them up, and played with them. We were told they were 'special'—because of the HIV. There was a lot of shit and a lot of throwing up."

"They needed a lot of love," said Mimi, "and that's what we gave them."

Mimi can describe dozens of children in loving detail—the criers, the sweet ones, the hyperactive kids, the clowns and the quiet ones. "We were like their mothers. Some of the child-care workers even adopted children from ICC," she said. "I wanted to, but I was living at home, and my mother and father didn't want to take care of another little baby at the time."

Besides feeding, changing and bathing duties, the child-care workers were also responsible for administering drugs to the infants.

"The nurses would lay out the drugs on the counter. Lots of pills, powders and oral syringes, all labeled for each particular child. We'd pick up the syringe and put it right into the mouth or into the tube if they had one.

"We didn't like it, but that was our job," said Mimi. "We were told that they would die without the drugs—and since we were with the kids the most, it was up to us."

"But over time," Mimi said, "we began to feel betrayed."

"In the beginning we were taking care of little abandoned crack babies who had no one, but then it changed. More and more of the kids were there for compliance. They didn't want to take drugs, or their parents didn't want to give them, so they got put in ICC.

"None of us ever blamed the kids for refusing. We all saw them throw up like clockwork after taking the pills, and then the diarrhea that followed.

When the kids were all younger—babies—they couldn't tell us the drugs made them sick. But when they got older they started to tell us, 'I don't want to take this 'cause I can't go to school, I feel worse when I take it.'"

"We all had doubts about what we were doing," Mimi said. "But honestly, we did what we were told."

One of the things Mimi and the other childcare workers noticed was the constantly shifting medicine regime. "Some children got AZT, some didn't. Then it would switch. Then it was a new drug, then it was a drug that we never heard of.

"We figured it out," she said. "These were experimental treatments." Marta, another child-care worker, put it more bluntly, "This is the guinea-pig business," she said.

ICC is administered by Columbia Presbyterian Hospital and the Catholic Home Bureau. It was under ICC's first medical director, Dr. Stephen Nicholas, that the orphanage began to receive funds from the National Institutes of Health to use its wards in pharmaceutical clinical trials.

ICC claims to have stopped the trials in 2002, but children from ICC are still seen at major New York hospitals, including Columbia Presbyterian, which all continue to do trials with HIV-positive children.

In 2005, following a year of media coverage on ICC, the New York City Council held a City Hall meeting to determine what exactly had happened there. Mimi attended.

"What a joke," she said. "They were trying to find out if ICC was doing trials... We were giving kids experimental drugs since the beginning. It was no secret. If you asked the nurses about it, you were told it was normal, and not to ask questions. If you asked the doctors why some kids got AZT and some didn't, you didn't get an answer."

"But we knew drug trials were going on," said Mimi. "The child-care workers, the nurses, the doctors, administration—everybody knew."

I asked how the children handled the complex regimen.

"The nurses said these children were lucky because they were getting the new drugs, but at the same time, when the kids vomited, or had diarrhea, or a bad rash," Mimi said, "we knew it was the meds. Even the nurses told us it was the meds. You couldn't hide it. It happened too regularly, it was predictable.

"Give the drugs, get ready for the vomiting and the shit."

"But we had to give them. We were always told that without the meds they would die," said Mimi.

"Is that what happened?" I asked.

"No," said Mimi. "It wasn't that predictable. Some kids lived and some kids died. But the ones who were drugged the most did worse." She added, "The ones with the tubes always did worse."

When Mimi started at ICC, the tubes were used infrequently. "But when the kids got older, a lot of them started to refuse the medication," she recalled. "Then they started coming in with the tubes more and more."

"Kids who refused too much, or threw up too much, they'd get a tube. First it was through the nose.

"But then it was more and more through the stomach. You'd see a certain child refusing over and over, and one day they'd come back from the hospital from surgery, and they had a tube coming right out of their stomach.

"If you asked why, the doctors said it was for 'compliance'—the regimen. Got to keep up the regimen," said Mimi. "Those were the rules."

"We weren't happy about it, because it wasn't just the drugs—it was everything that was getting pumped through the tube. Children would be pumped all night long with the milk—the PediaSure. It would pump so hard that the milk would leak out around the hole.

"Sometimes we'd turn off the pump for the kids, because it hurt their stomachs, but then the nurses would turn it back on. Some of the kids would do it themselves—they'd get out of bed in the middle of the night and turn off the machine. But in 20 minutes, it would start beeping, and the nurse would go back and turn it on."

"The children who were pumped all the time wouldn't have any appetite left, so they wouldn't eat. And then with the drugs on top of that, with the diarrhea, they wouldn't do well."

"But that was the rule," said Mimi. "Keeping to the regimen. Adherence. Give the drugs on time, on schedule, no matter what," Mimi repeated. "Or you're fired."

"Adherence" was the word of the day in late 2003, when I interviewed Dr. Catherine Painter, ICC's current medical director, about the relentless drug schedule. Painter explained, "What we're asking of our families and patients in terms of adherence is something beyond 100 percent—all of their medicines all the time, whether they have them on-hand or not, whether the medication makes them sick or not, or whether they're sick with a concurrent illness."

Michelle, a 17-year-old former resident at ICC, was there for just this reason. "I've expressed that I don't want to take the drugs, but they don't listen."

Michelle said that the drugs are given continuously throughout the day and night.

"I don't have to be up until 8:30, but they'd wake me up at 6 a.m. and give me meds. So I'd take the meds and go back to sleep. Then I'd wake up—and throw up. Because it was sitting in my chest and not in my stomach—and either way it doesn't feel good."

I asked Mimi why the children were drugged at night.

"The doctors and nurses gave us the drug schedule, and we had to follow it. Nine p.m., 12 a.m., 3 a.m., 5 a.m.—it didn't matter. We had cups full of pills and powders and oral syringes. It was up to us to figure out how to do it."

"So we learned to wake the children up, halfway, and pop it or squirt in their mouths and get them to swallow with a glass of water, and they'd fall back to sleep."

"How did the children react?" I asked.

"About half the time or more they'd wake up puking. We felt bad for them," said Mimi.

"At the time I thought it was better to get them to take the medication when they were half asleep and couldn't refuse, than to see them get a tube put in because they were refusing."

"But we all had our doubts," she added.

"One girl, a six-year-old, Shyanne—she came in for adherence. She was the most delicate little flower—beautiful, polite, full of life. Her family never gave her meds. So Administration for Children's Services brought her into ICC."

"So, she came in, and started the meds. And it was three months, maybe three months. And she had a stroke. She couldn't see. She was this normal girl, singing, jumping, playing. Then, poof, stroked out. Blind. We were freaked out. Then, in a few months, she was gone—dead."

Michelle, the 17-year-old, knew Shyanne. So did Deanna, a 16-year-old who was Shyanne's roommate.

"That poor girl is traumatized," said Mimi. "Can you imagine, you go to sleep and you wake up and they're taking away your roommate?"

The drug Mimi remembers giving most often at ICC is the nucleoside analog AZT. In addition to the drug's long list of severe and even life-threatening toxicities, AZT also been linked to lymphoma and other cancers.

Andre, a 19-year-old who spent years at ICC as a child and adolescent, told me that he never wanted to take the pills because he didn't like them. So he'd hold them in his mouth and spit them out later.

"What about when they'd drug you at night," I asked.

"Oh yeah," he said, remembering—his eyes widening slightly. "I remember that. I guess I did take them."

Last year, Andre was treated for lymphoma. He wonders if it was related to the AZT he was regularly fed as a young boy.

Mimi has encouraged him to get his complete medical records from the state, but he is having little luck getting through the system.

Andre's memories of ICC are mixed. He tells me that he loved the child-care workers, like Mimi, who looked after him. He just didn't like the drugs, so he didn't take them, when he had a choice.

Shawn, a 14-year-old boy who is still in state custody, has practically grown up at ICC. When I asked him what he thinks about ICC, he said, "I like ICC because my friends are there." He paused then added in a quiet voice, "But I don't like when people run away from shots or vaccinations, or have to get held down so they can give you a shot."

Shawn is also in ICC because he doesn't like to take the drugs, and Mona, his aunt and legal guardian, doesn't like to give him drugs that she claims make him weak and sick.

Shawn acts out—he runs away whenever he can to get away from the constant, monitored drugging. When he is returned to ICC, Shawn tells me, it's "needle time"—time for Thorazine shots, then off to a local psych ward.

"They're destroying him," his aunt Mona tells me. "He just wants to come home, it's so obvious. That's why he runs away."

"The regime has changed," said Mimi, "and so has the place. It's AIDS drugs plus—plus psych meds, anti-psychotics, antidepressants. We came to work here with kids we were told were dying—crack babies—to try to care for them. Today it's a psych ward."

In 1999, Mimi left ICC for nearly two years to have a baby. When she came back, ICC was under new management. The nuns who used to administer ICC had been replaced by a nursing-home bureaucracy, headed by Executive Director Carolyn Castro.

ICC's founding physician, Dr. Steven Nicholas, moved on to head Harlem Hospital's Pediatric division in 2001. Nicholas is also project leader and principal investigator for two ongoing HIV/AIDS projects in La Romana, Dominican Republic. Like ICC, these projects are funded and overseen by Columbia University in conjunction with the local church and state authorities.

Another important change at ICC was that the child-care workers now belonged to a union, and were no longer responsible for administering drugs.

"That was a relief," Mimi said. "After I became a mother, I didn't think the same way about things, about the drugs."

Rhonda, a former nurse from ICC, relates the story of how Marilyn Santiago, one of ICC's supervising nurses, suffered a needle-prick injury, and went on AZT, according to the current recommendation for healthcare workers.

"She was not well at all," said Rhonda, "Malaise, diarrhea, she was tired out, like she was going to die."

Mimi added, "She had it bad. She got a dose of her own medicine."

Rhonda pointed out that when Santiago got off the AZT, her system returned to normal.

AZT, the drug that is used in case of needle-stick injuries, is the same drug given to pregnant women and young children who test HIV positive worldwide. It was also used the ICC trials. AZT is often referred to in the mainstream press as a "life-saving" drug, despite the fact that it warns of the possibility of fatal anemia and organ failure on its label. A 1999 study in the journal AIDS reported that children born to mothers who are given AZT are sicker and die faster than those not given the drug. It is one of several recent studies reporting that AZT increases the rate of illness, major malformation and death in children whose mothers are fed the drug.

Mimi left ICC in December 2004. "I was fired," she said. "I let it happen. I couldn't stand it anymore—I watched them drugging this little boy to death—there's no way it was anything but the drugs."

Mimi described a boy named Seon, who died in spring of 2004.

"He had all these soft, fatty lumps. We even called him "lumpy." She said. They sent him to get the lumps on his neck removed in surgery, and they would just grow back. They told us it was cancer, but he was on all those drugs. He had a tube, and they were always pumping him. When we changed his diapers, it would come out like the drug mixture—rough and sandy like the ground-up pills."

Mimi said that after he died, she read about the phenomenon of "buffalo humps," large fatty lumps on the back and neck

that result from the newer AIDS drugs called protease inhibitors.

Rhonda, the former ICC nurse, and Mimi both remember another boy at ICC who developed a breast while on the drugs. "He had a mastectomy, and then the other one started to grow. They couldn't hide that it was because of the drugs, but with Seon, they told us it was cancer," said Mimi.

Mimi has a paper from ICC, that she saved from Seon's treatment. "One day I got a sheet from the nurses about a drug they were going to give Seon—it said any woman who was pregnant or who was of child-bearing age should not touch the drug, even with gloves on."

"I couldn't pronounce the name, so I kept the sheet. Thalidomide. That's what they gave him."

Thalidomide was originally marketed as a safe, over-the-counter sedative and analgesic in the 1950s and 1960s throughout Europe. It caused a wave of severe deformities in children of pregnant women who took the drug and was taken off the market. In 1998, the drug company Celgene resurrected Thalidomide, with FDA approval, officially as a leprosy drug, but with intended off-label use for AIDS and cancer patients.

"They pumped Seon with it; he deteriorated fast," Mimi said. "Once day we came in and he was bleeding from every hole in his body—his rectum, his nose, his mouth. He was in such pain. He would scream when he had to go to the bathroom. They put him on a respirator. They induced a coma with drugs so they could put him on a respirator. They told us they did it so he could breathe better." Mimi said, her voice getting a little rough. "I sat with him; he couldn't talk, but he was crying-tearing from his eyes. "He got all dry and scaly; he shriveled up like a snail-and he died."

"After he died, I just didn't care anymore. I didn't want to be there. I didn't want to quit, because I'm close with the kids—it was confusing," Said Mimi. "I'd been there for almost 10 years. But I couldn't stand it after that. So I stopped listening, and argued, and was insubordinate. They said I fell asleep in one of the rocking chairs for five minutes during an overnight shift. I said I didn't. They asked me to come in and talk about it, but I said fuck it. It didn't even matter. So they fired me. It was a relief."

After Mimi left, she was contacted by a half-dozen former ICC residents—children she'd helped to raise and take care of.

"We talk," said Mimi. "We talk about what's happened, and how they can live their lives now."

Michelle, the 17-year-old, is one of Mimi's post-ICC kids, who spent six months at ICC in 2004. She is now out of ICC and back in high school. Michelle admits that whenever she can, she weans herself off the drugs.

"When I was on the medication, it was hard. It doesn't make me feel good, and I have to deal with feeling sick and then trying to make it through my eight-hour day."

What happens when you quit?

"The withdrawal period is hard," she said. "I'm tired and I want to sleep all the time."

Michelle has been off the drugs for a few months, and says she feels better and stronger. "It's easier, I don't feel like I used to—12 o'clock comes and I feel hungry, but I don't get sick if I don't eat right away."

Michelle is out of ICC, but she's not free of New York's Drug Adherence program. She is required to attend weekly doctor appointments where her blood is drawn and tested for med levels.

What happens if the doctors decide you're not taking the drugs?

"They put you back in the hospital or in ICC—like that," she said, snapping her fingers. "They always say it's just going to be a short period of time, but it's always a few months—and that's out of my school time."

Michelle explained, "School is everything to me—I just want it out of my way so I can keep moving through life. I want to go to college—and high school is standing in my way"

"So it's comply versus school. Don't comply, and miss out on school. Then it's an extra year you have to do. So, smile and nod and take the pills, and slowly stop, or it's back to square one."

"I'm 17, not 18, and until I'm 18—I can say the sky is blue—and they'll say it's not—and I say 'Yes it is'—but it doesn't make a difference. Three more months," she said, her throat tightening.

"I'm telling you, I can't wait...I can't wait."

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