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Help, but Not Enough, for Girl Who Was Discarded Twice

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It was only a week ago that the tiny body of Stephanie Ramos was found in a plastic bag in a garbage truck in the Bronx, discarded by a foster mother who told the police that she panicked when the severely disabled girl died.

It was an ugly ending by any measure, but particularly cruel in this case because the little girl's life began the same way: wrapped in a plastic bag and discarded on a New York City byway.

In September 1994, days after her birth, Stephanie was discovered near her parents' home, those who have seen her records say. The lack of oxygen in the bag probably contributed to mental retardation so profound that even when she reached age 8 she had only the awareness of a child younger than 1. She weighed 28 pounds. Although the records are unclear as to blame, the infant's parents quickly lost their rights to care for her and she became a ward of the state.

The almost unspeakably grim end occurred despite intense intervention from the state practically from the girl's birth. The eight years of Stephanie's life, the years between trash bag and trash bag, offer a glimpse into the unevenness and unpredictability of care for perhaps the most vulnerable of New York's citizens, severely disabled foster children.

In some areas, Stephanie received extraordinary services. An ambulance drove her every day to school, where she was watched over by her own private nurse. Her senses were coaxed with stuffed animals and soft music.

But her care was also marred by inexplicable oversights and lapses. She bounced among foster homes, traveling through three in eight years. Law enforcement officials described the Queens home of the final foster mother, Renee Johnson, as filthy and unsanitary. Even the gastrointestinal feeding tube that kept Stephanie alive, they said, was caked with grime and weeks-old formula.

Advocates for disabled children say the lotterylike nature of the foster care system, where the child's care depends on the diligence of the agency they are placed with and the foster care worker to whom they are temporarily assigned, is particularly exacerbated in the case of multiple-needs children who require so many extras.

"It is a monumental system," said Margaret Mikol, the executive director of Sick Kids Need Involved People, a nonprofit organization that assists parents of disabled children in getting services they require. "There is no consistent person who stays with you to help you sort through it."

Ms. Johnson is being held in \$50,000 bail in Manhattan on charges of improper disposal of a body and falsely reporting an incident, and on a felony charge, tampering with evidence, while an autopsy is being completed. But Stephanie's doctors have told law enforcement officials that the child, who was blind and suffered from cerebral palsy as well as diabetes, could have died from complications at any moment.

Murray Singer, a lawyer for Ms. Johnson, said, "She certainly did not hurt or kill this girl."

Stephanie's journey in foster care began days after her rescue from the plastic bag. There are roughly 45 nonprofit agencies that contract with the city to provide foster care services, but only 8 of them handle the severely disabled. Through a combination of happenstance and availability, Stephanie was assigned to the

Association to Benefit Children, which has consistently ranked among the bottom in recent city evaluations of such service providers. The association asserts that the rankings resulted from the city's entering incorrect data into its computers.

The Association to Benefit Children is also being investigated by the police. Law enforcement officials said yesterday that the focus of the investigation was narrowing on a nurse and a caseworker responsible for supervising Ms. Johnson. Yesterday, Susan Brune, a lawyer representing the agency, met with investigators.

Stephanie spent the first six years of her life with a foster mother who many in the system agree was incredibly dedicated, but often overwhelmed. One person who had seen the records from Stephanie's first years with the foster mother said that the Association to Benefit Children provided the child with medical services, including an endocrinologist to manage her diabetes, and an array of speech and language therapists.

But the mother was not being helped to gain access to many other services that would make life with such a challenging child more bearable. She got no homemaker services, no baby-sitting, no in-home nursing, the person who saw the record said. The foster mother was also paying for a neurologist and a pediatrician out of her own pocket. Ms. Brune said the association could not comment on the earlier home.

Helene Craner, associate director of Resources for Children with Special Needs, a nonprofit advocacy group, said that burnout is an enormous problem for foster parents of children with disabilities because they often do not get the respite they need. "The foster care agency should be providing the services, but in a lot of cases what is supposed to be happening does not happen."

Despite the first foster care mother's sterling record, the agency removed Stephanie from her care at age 6. The city wanted Stephanie to be adopted, but the first foster mother was not interested in that permanent commitment, said Maclean Guthrie, a spokeswoman for the Administration for Children's Services.

The child was bounced to another placement, which lasted two months. The second foster mother found the child's needs overwhelming, Ms. Guthrie said. Then in 2001, Stephanie was placed with Ms. Johnson, a 50-year-old retired nurse.

The association had not done a background check on Ms. Johnson, Ms. Brune said. Instead they reviewed the paperwork -- which they say they are allowed to do by law -- done by the foster care agency Ms. Johnson had worked for previously. Although Ms. Johnson had never adopted a child and already had another severely disabled child in her home, they said she was a more promising prospect than the first mother.

From the first, the association found that the match worked well. Her doctors and school said that Stephanie was doing well and gaining weight, Ms. Brune said. Stephanie attended an off-site annex to the Marathon School in Queens, which is especially for children with multiple handicaps.

During the day she was attended by a private nurse paid for by Medicaid. In April of this year, the nurse, Mary T. O'Leary, wrote a note to other educators praising Ms. Johnson. "Her clothes are of the latest fashion; with accessories for her hair that always match her outfits," the nurse wrote in the note, which was given to The New York Times by the association. The note also said that Ms. Johnson always provided medical equipment, medicine and information crucial to Stephanie's upkeep in a timely manner.

The description of Ms. Johnson as meticulous and conscientious contrasts with the conditions the police say they found in her house a day after Stephanie's death. Last week in Manhattan Criminal Court, an assistant district attorney, Joan Illuzzi-Orbon, described the home as covered with hair, feces and insects.

Ms. Brune said she cannot explain the discrepancy. "Everything in our case records indicate that she was taking excellent care of the child," Ms. Brune said. "During a three-year period, there were many people in and out of the home and all have described the same thing. They say that the house was very cluttered with many possessions, including toys for the children and clothes. But despite the clutter, they saw the

house was clean."

The lawyer said there was one other puzzle. Despite caring for three foster children, two with exceptional needs, Ms. Johnson was getting no services at home. A nurse service was canceled in November, according to the city agency, but Ms. Brune said the services had been terminated without the association's knowledge.

Ms. Brune said she suspected that the investigation would focus on nurse services as well as on the month after the last inspection of the home in June.

"The issue that is going to be the focus of the investigation is what happened between June 9 and the time of Stephanie's death," she said.

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