Complaints to agencies rarely result in action

Should handicapped infants be "allowed to die" with the consent of parents and doctors? This series probes questions about these children — the 5,000 annual "Baby Doe" cases — that deeply divide medical, legal and government authorities.

Third in a series

By Carlton Sherwood THE WASHINGTON TIMES JULY 11 1984

While Justice Department and Health and Human Services Department officials are now refusing even to acknowledge "Baby Doe" complaints, neither federal agency has much of a track record when it comes to taking action on hundreds of cases previously referred to it for investigation.

Government files and correspondence obtained by The Washington Times show that in the past, federal officials have been slow to investigate reports of infant abuse, and, when preliminary inquiries failed to disprove a complaint, they have been even more reluctant to take further action.



Records demonstrate that most cases referred to HHS and virtually every complaint sent to the Justice Department have remained in a state of limbo, officially unresolved, for months and even years without action.

In two years, the Justice Department has conducted only one "Baby Doe" investigation. That case involved a report that a child born with spina bifida — an exposed spine — was being allowed to die untreated in an Illinois hospital.

Robert D'Agastino, the Justice Department attorney who handled that investigation, said he found "clear violations of federal laws" but, because the baby was eventually treated and lived, no charges were filed.

From April 1982 to December 1983, HHS reports it launched investigations in more than 150 incidents involving alleged withholding of medical care from

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tal handicaps.

Of those, only 31 were officially closed - either because no violation was found or because the original complaint failed to provide enough information to conduct a thorough inquiry.

The remaining "Baby Doe" cases, some two years old and involving hospitals in Indiana, California, Texas, Michigan, Maryland, Florida, Louisiana, New York, Oregon, Nebraska, Virginia and Arizona, continue to be classified by HHS as "under investigation" or

"not yet completed."

Even the original "Baby Doe" case, the first to be filed with the federal government following the April 1982 death of a Down's syndrome infant in a Bloomington, Ind., hospital, remains officially unresolved. "Final administrative action has not yet been taken," HHS records say.

But perhaps the best example of how federal officials have dealt with past "Baby Doe" incidents involves a formal complaint filed by state Sen. Regina Smith, the chairwoman of the Connecticut Public Health Committee.

On June 17, 1982, Sen. Smith, a veteran Democratic legislator, sent a three-page letter to the Justice Department, urgently requesting federal investigations into the questionable deaths of a number of infants born with physical and mental handicaps in hospitals throughout the state — particularly in facilities affiliated with the Yale-New Haven Medical School.

Accompanying the letter addressed to the Justice Department's civil rights chief, Assistant Attorney General William Bradford Reynolds, were reams of supportive documents and testimony amassed by the state Public Health Committee during a year-long investigation of the state hospital system.

Included in those materials was a New England Journal of Medicine article written by the Yale-New Haven Hospital's pediatrics chief, Dr. Raymond Dutt, acknowledging that during a 20-month period 43 handicapped newborns died in the hospital's intensive care unit after medical care was withheld or withdrawn.

The state health committee itself, Sen. Smith wrote Mr. Reynolds, turned up 20 additional cases where many handicapped infants who might have survived without "heroic or extraordinary measures" died after decisions were made to withhold treatment and again, in some cases, food and water. Those incidents, she explained, were uncovered during a random sampling of death records in just 11 hospitals over a single six-month period.

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Specifically, Sen. Smith asked for federal investigations into committee reports that:

- · "Babies were allowed to starve to death because they were born with Down's syndrome" - in one case over a 23-day period.
- Parents with handicapped newborns were "given lethal overdoses by physicians to administer to such babies at home."
- Doctors "falsified death certificates in such cases."

Sen. Smith says she expected a response to her letter within a few days, "if only a simple courtesy call saying they received it.'

When none came after two weeks, she telephoned the Justice Department to confirm the letter had arrived.

"They said it had, and I would be hearing from someone soon," she

Several weeks passed, and she made more calls — with no apparent success.

"After a while, I finally stopped calling and just waited," she said.

On Feb. 14, 1983, eight months after the complaint letter was filed, the first official acknowledgment came in — but it wasn't from the Justice Department.

Caroline Chang, director of HHS's Boston regional office, wrote to inform the state legislator that the office had just received the materials Sen. Smith had sent to Washington the previous spring and was now planning to "initiate our processing of your complaint."

Mrs. Chang told Sen. Smith that her office would "complete its investigation in approximately 90 days" and, "if no violation is identified," both she and Yale-New Haven hospital would be notified "in writing."

That was more than a year ago. It was also the last Sen. Smith heard from any federal agency concerning the complaint she filed two years ago last month.

HHS records list the Yale-New Haven Hospital investigation as "continuing,"

Sen. Smith is skeptical and, she says, frustrated.

"Bureaucratic procrastination could account for some delay but not this," she said. "The problem is that, when you're dealing with hospitals, you're dealing with powerful institutions, the sacred cows in every community.

"How dare anyone go in and suggest something is wrong, something unethical is going on? Physicians are always the good guys in our society. Now all of sudden some of us are finding out there are some doctors out there who think you're better off dead because you happen to be retarded, or you might sit in a wheelchair.

"Of course, that's criminal," she said. "But when we have doctors actually admit in writing and under oath that this is going on in the hospitals and when we have these lives at stake . . . and then for the federal government to move at this slow pace — to do nothing for years that is a criminal act in itself."

Tomorrow: HHS Secretary Margaret Heckler at center of "Baby Doe" policy battle.