HHS beats retreat on newborn rights

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.

Fourth in a series

By Carlton Sherwood
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Earlier this year, Secretary of Health and Human Services Margaret Heckler wrote to Douglas Badger, legislative director of the Christian Action Council, to assure him of her position on the "Baby Doe" issue.

"I have always been, and continue to be, a committed advocate of protecting the rights of handicapped infants," Mrs. Heckler said in the March 23 letter. "As secretary of health and human services, I consider the Infant Doe problem to be critical. We are confident that the January 12 regulation, which is based on Section 504 of the Rehabilitation Act of 1973, is a strong and effective means of safeguarding the civil rights of newborns. That regulation will be rigorously enforced."

The theme and substance of Mrs. Heckler's comments had a familiar ring. For nearly two years, she and other administration officials, including President Reagan himself, vowed to crack down on hospitals and doctors who denied handicapped newborns the medical treatment they required to survive.

But internal HHS records and interviews with administration officials show that even while Mrs. Heckler was expressing her commitment as a Baby Doe "advocate," HHS had already struck a private agreement in a New York federal court to "delay direct investigation of complaints," including reports

Government's duty is to protect life. An editorial, page 11A.

that at least 24 infants died in an HHS-funded institution under orders they not be medically treated.

Records and interviews also demonstrate that, at the same time Mrs. Heckler was promising to "rigorously" enforce federal regulations, she failed to activate a special "Baby Doe" investigative unit — reversing her own earlier decision and the recommendations of the U.S. surgeon general that an "autonomous" investigative office was necessary to enforcement.

For administration officials who had spent months trying to find acceptable federal protections for handicapped newborns, the signals were clear — by March of this year

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Surgeon general is big loser in battle at HHS

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"Baby Doe" as a federal matter had become "moot."

The decision to retreat from the "Baby Doe" issue was preceded by nearly two years of intensive infighting among HHS officials, who remain bitterly at odds over whether the federal government, or any law enforcement agency, should involve itself in such cases.

The big loser

At the center of the bureaucratic conflict is U.S. Surgeon General C. Everett Koop, by all accounts the big loser in the long-running internal battles at HHS.

Ironically, Dr. Koop is also the administration's chief spokesman on "Baby Doe" regulations and one of the few federal officials who has tried to implement President Reagan's policy directives that "federal laws prohibiting discrimination against the handicapped ... be vigorously enforced."

When he took office in 1981, Dr. Koop was excoriated by feminist organizations, legislators and the press for his outspoken views against abortion, which, he predicted, would lead to the deliberate withholding of medical care from handicapped newborns — or what he called "infanticide."

Despite his credentials as one of the country's first pediatric surgeons, Dr. Koop's "infanticide" remarks did little to endear him to his medical colleagues — much less his associates at HHS, many of whom vehemently disagreed with his pro-life opinions.

Just how deep those differences are became apparent following the April 1982 death of a Down's syndrome infant in a Bloomington, Ind., hospital.

Almost from the day President Reagan ordered federal protection for handicapped newborns, the official chosen as the administration's Baby Doe "point man" found himself mired down in a massive bureaucracy unaccustomed to taking punitive action against doctors or hospitals.

"Traditionally, HHS has been run by and for the medical community, with doctors and hospital administrators in key slots throughout the agency," an administration official familiar with HHS operations said. "When he was a surgeon and hospital administrator, Dr. Koop was used to having his own orders followed. That's where he made his first mistake here — believing that he or anyone, even the president, could release the medical profession's stranglehold on HHS."

Open indifference

While the surgeon general was given the job of publicly echoing the administration's "Baby Doe" policy, the authority to enforce violations of the government's anti-discrimination laws was delegated to HHS's civil rights office, headed by Betty Lou Dotson, a career government employee who previously served as an equal opportunities lawyer at the Department of Agriculture.

HHS and White House officials who asked to remain anonymous say that initially the surgeon general was "astounded" by the "open indifference" of the HHS civil rights staff to the president's policy directives.

Under federal regulations related to Section 504 of the 1973 Rehabilitation Act, the civil rights office of HHS is required to conduct "prompt" investigations of all "Baby Doe" complaints and, if an initial inquiry determines a violation might have occurred, to forward that information to the Justice Department for action.

Within weeks after President Reagan issued his 1982 policy directive, HHS received its first major "Baby Doe" complaint — a formal request by the chairwoman of the Connecticut Public Health Committee for federal investigations into the deaths of at least 65 handicapped infants at the prestigious Yale-New Haven Medical School and several affiliated hospitals around the state.

The complaint letter, filed in mid-June by state Sen. Regina Smith of Connecticut, alleged that certain infants were being targeted for non-treatment and, in some cases, were being deprived of food and water.

When, after a month, the HHS Civil Rights Division had still not begun an investigation of the Connecticut complaint, Dr. Koop and several other administration officials asked for a meeting with Miss Dotson.

"It was a disaster," an administration source who attended that meeting recalled. "Right off, she [Miss Dotson] said the complaint had been misplaced or lost, but it was apparent she didn't even know anything about it. It was also painfully clear that she didn't care to know anything about it or any other case for that matter. Her position seemed to be that 'Baby Doe' cases were an oddity — extremely rare situations — and that most complaints, like Connecticut, were probably false since the media hadn't already made an issue of them."

Nine months later, following an inquiry from a New England television station, HSS authorized an investigation into Sen. Smith's allegations. However, HHS records continue to list the two-year-old complaint as under investigation.

Throughout fall 1982, administration officials said, Dr. Koop tried repeatedly to persuade the civil rights director and her staff, including HHS attorneys, "to take the 'Baby Doe' issue seriously."

"He warned them that this would not pass ... It was a serious problem and sooner or later it would come back to haunt the administration," an administration official said. "Essentially, he was ignored, written off as a pro-life zealot."

Get-tough policy

All that changed, or seemed to change, when in March 1983 Margaret Heckler, a former Massachusetts congresswoman with a strong anti-abortion voting record, was sworn in as the new secretary of HHS.

Months before her appointment was made official, Mrs. Heckler was briefed by Dr. Koop and others concerning the apparent refusal of the civil rights office to move on "Baby Doe" complaints. While the incoming HHS secretary was reluctant to follow suggestions that Miss Dotson be replaced, she agreed with the surgeon general and others that HHS had to be more aggressive in its enforcement of "Baby Doe" cases.

As part of a new get-tough policy at HHS, Mrs. Heckler announced at her Senate confirmation hearings that all federally funded hospitals would be required to post a 24-hour, toll-free hot line phone number in their infant care wards along with a notice that discriminatory treatment of handicapped infants was prohibited under federal law.

The creation of the hot line was applauded by most pro-life organizations and several national organizations for the handicapped previously known for their criticism of the Reagan administration.

But it outraged virtually all the largest national medical associations, which complained that the notice was disrupting normal hospital operations and unjustly holding doctors up to suspicion and criticism by parents and even other medical personnel.

The medical organizations, including the American Medical Association and the American Academy of Pediatrics, took the matter to court, arguing that the "Baby Doe" hot line notice had been issued by HHS without the required period for public comment.

A Washington federal court judge agreed, and, less than three months after it was issued, the notice was ordered removed from hospitals.

As the administration's chief defender of the hot line, Dr. Koop absorbed most of the criticism from the medical organizations. HHS officials say that any good will left between the surgeon general and his medical colleagues all but evaporated.

Nonetheless, the same officials say the hot-line notice demonstrated at least two things.

First, it proved that, contrary to opinions expressed publicly and within HHS itself, "Baby Doe" cases were not all that rare. During its short existence and, despite the refusal of many hospitals to post the notice, the hot line generated dozens of complaints alleging handicapped newborns were being deprived of medical care.

It also showed that, even when confronted with reports of "Baby Doe" violations, HHS's civil rights office was either unwilling or unable to move on the cases. None of the allegations received or investigated by HHS during spring 1983 was ever referred to the Justice Department, and dozens remain listed by HHS as still under investigation.

Medical compromise

HHS sources say that, while Mrs. Heckler "sympathized" with the surgeon general's critical assessment of the civil rights office's performance, she and other administration officials believed the "priority had become finding a workable protection mechanism which would not be met with total opposition from the medical organizations."

From August through September 1983, administration sources say, Dr. Koop orchestrated a series of closed-door meetings with representatives of the major medical organizations in an effort to hammer out mutually acceptable regulations.

Representatives of the AMA maintained their steadfast refusal to endorse any "Baby Doe" laws. But several other organizations, including the Academy of Pediatrics, agreed to the negotiations.

The result of those meetings was a new set of regulations authorizing hospitals to appoint a committee of lay and medical personnel to deal on a case-by-case basis with the treatment of handicapped infants. Under the proposed regulations, non-treatment of infants based on handicap was still prohibited, but violations would first be referred to state child-protection agencies before being passed on to the federal government.

Privately, the surgeon general hailed the agreement as an outright victory, telling friends and administration colleagues that "we got 95 percent of what we wanted."

But when word of the compromise leaked out, Dr. Koop found himself on the firing line once more. This time, however, his critics consisted of longtime supporters in various pro-life organizations, who characterized the hospital review committees as "God squads" and accused the surgeon general himself of "selling out" on the "Baby Doe" issue.

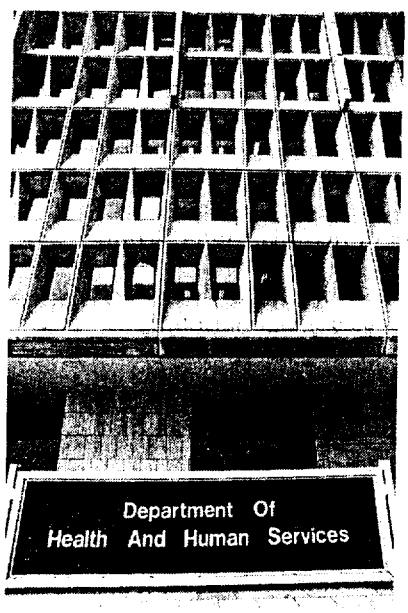
Administration sources say that, while Dr. Koop was "stung" by the recriminations, during the same period last fall he began receiving "positive signals" from Secretary Heckler that she was finally prepared to deal with the matter of enforcement by her own civil rights office.

"As a practical matter, Dr. Koop told the secretary that it didn't make much difference what regulations were adopted if HHS's civil rights office wasn't prepared to enforce them," an administration source said. "As a political matter, Mrs. Heckler said she wasn't prepared to fire her own civil rights director for incompetence — but she did suggest an alternative."

That "alternative" was spelled

"The message was clear by that time. If the surgeon general, who had a good relationship with Mrs. Heckler, could be outmaneuvered by her advisers, there wasn't much chance that anyone else could effect a change.... Baby Doe had become moot."

— An aide at HHS.



out in a confidential "decision memorandum" sent to Secretary Heckler from the surgeon general on Feb. 10, 1984 — a month after the new "Baby Doe" regulations were formally announced and three days before they became effective.

"In our last discussion, you suggested a new unit for the enforcement of the rights of handicapped infants that would report to the secretary through the chief of staff under the policy direction of the surgeon general," Dr. Koop wrote. "I recommend that the unit be designated as the Office of Handicapped Infants' Rights and, for the near future, be administratively located in the Office of Civil Rights but autonomous of that office."

Aside from cementing an earlier agreement to create a special investigative unit, the memo also sought to formalize the appointment of a director for the new office before any new "Baby Doe" complaints were filed.

The surgeon general advised Mrs. Heckler that "in order to begin action immediately," she should name a director for the office "as soon as possible."

Investigator selected

The question of who would head up the 22-member unit had already been settled, HHS sources said. A Federal Trade Commission lawyer with a background in investigative work had been interviewed by both Dr. Koop and Mrs. Heckler and selected to direct the "Infant Rights Office" when the new regulations went into effect and the investigative unit was legally established.

The special investigator had his work cut out for him. Weeks earlier, Dr. Koop and others at HHS and the White House were told to expect a formal complaint concerning the deaths of at least 24 handicapped infants at a hospital in Oklahoma.

"There was no question that the Oklahoma cases were first on the agenda — they would be the test case under the new regulations," an administration official said. "We'd all been briefed on the situation, and, from what the doctors involved said and wrote about the infant deaths in Oklahoma, it represented the clearest and least entangled example of potential violations — possibly the best case ever referred to HHS."

In his memo to Secretary Heckler, Dr. Koop stressed the need to "resolve pending problems, whether of substance or of public perception" concerning past "Baby Doe" cases. He also said HHS should "develop a system of consistent, centralized and professional response to all future cases" and "must move quickly to effectively implement this important initiative in a professional manner."

Sudden shift

Six days after the surgeon general filed the memo, Secretary Heckler, on the advice of her Chief of Staff George Siguler, authorized the creation of a new office — "assistant director for policy in the Office of Civil Rights" — but it had no resemblance to the one she had previously discussed with the surgeon general.

For one thing, the position was not "autonomous." For another, it carried no investigative powers. Instead, the new office, which remained vacant, was designated to conduct "a research program to develop and maintain a body of information on civil rights issues."

According to administration officials, the surgeon general was "stupefied" by the turnabout in policy direction.

"He [Dr. Koop] had worked for months scratching out a compromise on the new regulations and, like the good soldier he is, taking all the public heat which would have been directed at Heckler," an HHS source said. "Sure, he felt betrayed.... He expected better from the secretary."

Effectively, administration officials said, Mrs. Heckler's refusal to create an enforcement unit signaled the end of any government involvement in the "Baby Doe" issue. When the formal complaints on the Oklahoma deaths and other reported "Baby Doe" cases were filed with HHS later in February, Miss Dotson's civil rights office declined even to acknowledge them.

In March, following the initial filing of a lawsuit challenging the new regulations in a New York federal court, HHS officials formalized their non-enforcement policy by privately agreeing not to investigate "Baby Doe" cases.

That decision was recently confirmed by Miss Dotson, who explained in a July 2 letter to an attorney who had filed the original complaints concerning the Oklahoma deaths that "in order to avoid a preliminary injunction in March, the department agreed to delay, until resolution of the litigation, direct investigations of complaints."

"The message was clear by that time," an HHS aide said. "If the surgeon general, who had a good relationship with Mrs. Heckler, could be outmaneuvered by her advisers, there wasn't much chance that anyone else could effect a change. In a political sense, Dr. Koop lost. Baby Doe had become moot."

Tomorrow: Congress takes action on "Baby Doe."

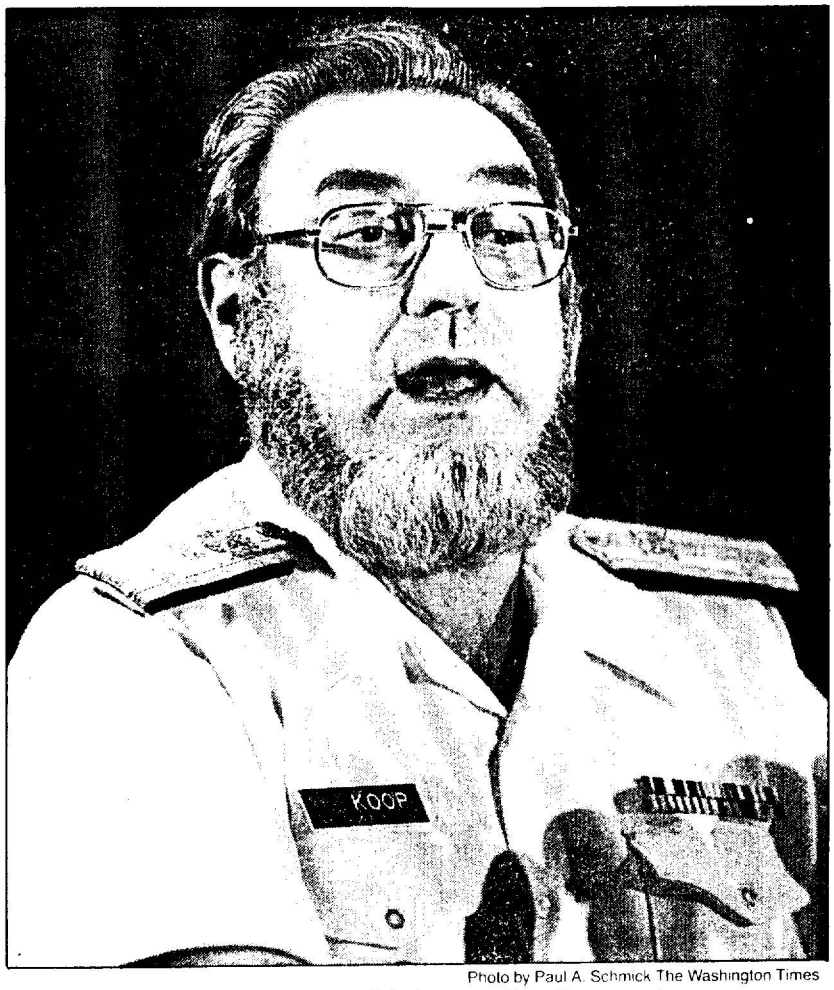


Photo by Paul A. Schmick The Washington Times

Surgeon General C.Everett Koop felt "betrayed" by the secretary.

Photo by Dayna Smith The Washington Times

HHS Secretary Margaret Heckler reversed herself on enforcement.