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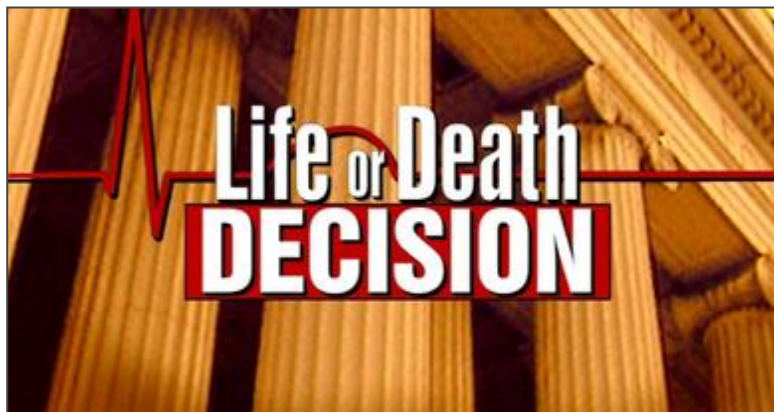
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Lawmakers look to clarify how DSS deals with end-of-life choices

BOSTON -- Of all the sad details about the case of 11-year-old Haleigh Poutre, one of the most heartrending was the decision by the Department of Social Services to seek to remove the feeding tube from the brain-damaged girl when doctors said there was no hope of recovery.



That decision, and the subsequent criticism that the state moved too quickly after Haleigh improved enough to survive without the tube, prompted an exhaustive examination of how the state handles end-of-life questions for children in its care.

Despite the attention given to Haleigh's case, the question of when to remove life-sustaining care from children in state custody is far from rare.

Since October 1993, there have been 54 recommendations that the state forego or discontinue life sustaining medical treatment for children in state care. In the vast majority of cases -- 81 percent -- the underlying medical condition was due to birth defects or terminal illnesses.

In at least 10 of those cases, including Haleigh's, the medical condition that led to the recommendation to end treatment was the result of abuse or neglect.

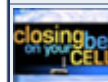
Now lawmakers are looking at ways to overhaul how the agency charged with protecting the state's youngest residents deals with impending deaths -- from making public the end-of-life hearings to codifying end-of-life protocols into law.

"It's the gravest of all decisions that the government can make, to recommend that someone forego life-sustaining treatment that could result in their death," said Rep. John Rogers, who led a special legislative commission looking into child abuse and neglect in Massachusetts.

In Haleigh's case, the Supreme Judicial Court agreed with the medical recommendations brought to the court by Social Services, finding she was "in an irreversible and permanent coma, with the least amount of brain function that a person can have and still be considered alive." Haleigh allegedly was beaten into a coma by her adoptive parents.

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"The medical evidence is incontrovertible," the court found. "The child is in a persistent, vegetative state and there is no medical treatment in the foreseeable future that can restore her cognitive abilities."

Soon after the court issued the ruling, however, Haleigh showed improvement and later moved to a rehabilitation center.

Massachusetts Secretary of Health and Human Services JudyAnn Bigby, who oversees DSS, said the agency has taken steps in the wake of Haleigh's case to improve its guidelines when dealing with end-of-life situations.

Bigby also said it's important to realize that when the state goes to court seeking to remove a feeding tube, it is doing so on the recommendation of medical professionals treating the children.

"The overwhelming number of child who die in DSS custody were either born with a severe terminal illness or acquired a severe terminal illness," she said. "The protocol that DSS has right now is a very thoughtful protocol and makes sure that everyone who should be involved is involved."

Bigby said she's worried about the effect that opening end-of-life court hearings would have on the families of the children.

"It's the medical providers who are making these decisions recommending this course of treatment, so I'm not exactly sure I see the relevance" of opening the hearings, Bigby said.

Rogers said he's spoken with Bigby and might be willing to tighten the recommendation on public hearings to only include those children who are the victims of abuse and neglect, and exempt those suffering from birth defects or illness.

One of the strongest voices in favor of opening DSS end-of-life court hearings to the public comes from a member of the state's highest court.

In the Haleigh Poutre decision, Supreme Judicial Court Judge Francis Spina made an impassioned argument in favor of opening similar hearings to the public, despite the fact that so-called "care and protection hearings" for children are typically closed.

The public, according to Spina, has a right to be assured those acting to end extraordinary medical care are acting in the child's best interest.

"The public is entitled to know that those seeking the orders are not trying to conceal foul play, or that the expense of maintaining life is not driving the request," Spina wrote. "Decisions of this gravity, made with this concentration of government involvement, should be made in public."

Among the protocols developed by DSS after the Haleigh Poutre case is the requirement that the physician treating the child make a written recommendation to the agency asking to end life-sustaining care.

DSS is then required to get a second opinion from another doctor not affiliated with the hospital, and -- if a decision is made to ask the court to order the end of treatment -- that DSS first ask the court to name a guardian for the child to review the request and make an independent recommendation to the court.

The DSS commissioner has the final say whether to seek the court order.

One of the recommendations of the commission chaired by Rogers is to write those protocols into state law.

Sen. Richard T. Moore, D-Uxbridge, Senate chairman of the Health Care Financing Committee, said a new resource available to children in DSS custody with terminal illnesses is the state's Pediatric Palliative Care Program created as part of last year's landmark health care law.

The program provides otherwise unavailable hospice care for children with life-limiting illness and their families.

Moore also said he's skeptical of make end-of-life hearings public.

"When you're dealing with kids it has to be treated in a more private manner," he said. "The first issue that DSS has to be concerned about is what's in the best interest of the child."

In decisions fraught with as much medical, emotional and ethical questions as end-of-life hearings, the state's top priority should be to protect the child, according to C.J. Doyle, executive director of the Catholic Action League.

"One of the primary duties of government is to protect human life and in all matters where there is any doubt, the presumption should be for the preservation of life," he said.

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