

THE
CHILDREN'S
HOSPITAL
OF
PHILADELPHIA

FOUNDED 1855

April 21, 1983



ONE CHILDREN'S CENTER
34th STREET AND
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C. Everett Koop, M.D.
United States Surgeon General
Department of Health and Human Services
Washington, D.C.

Dear Doctor Koop:

A number of residents at The Children's Hospital of Philadelphia have found it imperative that we, as a group, express our disagreement with the Interim Final rule "Nondiscrimination on the Basis of Handicap" and applaud its overturning on April 14 by U.S. District Judge Gerhardt Gesell. We oppose the posting of the notice: "Discriminatory failure to feed and care for Handicapped Infants in this facility is prohibited by federal law" and especially we oppose the establishment of a hotline which, according to the ruling, is to be used thus: "Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact: Handicapped Infant Hotline."

This rule has also failed to define what is meant by "customary care." As stated by the American Academy of Pediatrics, "As new medical findings are reported, new equipment added, and additional experience gained, standards of care are modified rapidly and frequently. There are also legitimately differing views of the appropriate treatment for the same conditions." Technology bears with it its responsibilities, including the need for the continued dignity of the dying child and his family. The issue, in our experience at Children's has never involved the decision as to whether to support an otherwise stable handicapped child, but rather the long, thoughtful decision made jointly by physicians, nurses, parents, social workers and at times clergy, of when not to prolong the life of a desperately ill child with little chance of leading anything close to a normal life. We would welcome the formation of a formal bioethical committee which, as proposed by the American Academy of Pediatrics, would provide a "more reasoned step-wise course" and guidelines for the humane resolution of "ethically complex situations."

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We find it ironic that this ruling should be implemented at the precise time of flagrant federal budget cutbacks affecting the poor and handicapped, paralleled by rising infant mortality. This is exemplified by the 1982 budget changes whereby the school breakfast program was cut by 20%, the school lunch program by 30%, the Child Care Food program by 30%, the Special Milk program by 80%; marked curtailment in the benefits to parents with children on home ventilators such that this program is in jeopardy of being discontinued, 20% cut in the Sprang's Grant - special project for funding of services to severely handicapped children, e.g., with spina bifida, craniofacial abnormalities, cleft palate, and speech and hearing deficits to name only a few.

We can only conclude from these actions that the government has taken only a superficial look at these complex issues and does not have at heart the total care of these children, i.e., their emotional, medical, nutritional and socioeconomic needs.

In short, the issues involved are not black-and-white and cannot be dealt with by simplistic measures. We need thoughtful, reasoned and loving approaches to each individual child's needs.

Cordially,
Members of The Children's Hospital of Philadelphia Housestaff

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