

# DRAFT

## MEMORANDUM TO THE SECRETARY

FROM: Juan A. del Real  
General Counsel

SUBJECT: Proposed "Infant Doe" Guidelines

### Issue

What action should the Department take to more effectively deal with Infant Doe cases?

### Summary

This memorandum proposes the issuance of guidelines designed to focus primary responsibilities on State child abuse and neglect agencies for the protection of Infant Does. The primary thesis of the guidelines is to strengthen the bridge between physician-parent deliberations regarding medical treatment and existing State legal and administrative structures for the protection of children. The guidelines would:

1. give notice that HHS interprets existing Section 504 regulations to require health care providers to report to the State child abuse agency suspected cases of unjustified withholding by parents of available life-sustaining medical treatment to infants with life-threatening congenital impairments; and
2. give notice to State child abuse agencies that HHS interprets existing section 504 and Child Abuse and Neglect regulations to require effective action to protect Infant Does.

The guidelines would be published in the Federal Register, and public comment would be solicited.

### Background

On May 18, 1982, in response to instructions from the President to the Secretary, Betty Lou Dotson issued a Notice to Health Care Providers reminding them of the applicability of Section 504 of the Rehabilitation Act of 1973 to Infant Doe cases. The Notice was limited to Section 504 responsibilities of health care providers which receive Federal financial assistance, and did not deal very specifically with the complications involved when parents withhold consent for medical treatment of an Infant Doe. These guidelines would be an effort to deal with those complications.

### Discussion of Significant Issues

#### 1. Guidelines versus regulation.

For several reasons, this memorandum recommends issuance of guidelines rather than regulations. First, guidelines, unlike regulations, do not need the approval of the Justice Department and OMB, thus avoiding what in a number of instances has proven to be a very lengthy and cumbersome process. Second, guidelines provide greater flexibility to the Department to adjust to unanticipated circumstances in an area with which we have had little experience. Third, because nothing in the guidelines is not supportable on the basis of existing regulations, issuing the substance of the guidelines as a new regulation is not necessary.

#### 2. Responsibility to provide medical care.

The guidelines seek to establish a standard for when medical care must be provided to an infant with a life threatening congenital impairment. That standard is embodied in both the section 504 responsibilities of health care providers and child abuse agencies that receive Federal funding and in the responsibilities of parents under child abuse and neglect laws. In cases where the withholding of treatment is by a health care facility and does not involve parental withholding of consent, the focus is on the hospital's section 504 responsibilities. Where the withholding is based on a lack of parental authorization for the treatment, the focus shifts to the State agency's responsibilities under both section 504 and the Federal child abuse and neglect program regulations. The "shifting" mechanism is the responsibility of hospitals under section 504 to report such cases to the State agency.

The substance of the standard for when medical treatment must be provided is whether it will benefit the infant. The guidelines set forth four situations where the infant will

not be considered able to benefit: 1) imminent death regardless of the treatment; 2) undue risk of death or worsening the condition; 3) best prognosis for treatment is for noncognitive existence; and 4) best prognosis is very short life with extreme pain and suffering. ?

3. Responsibilities of health care providers.

The guidelines repeat the points made in the May 18 Notice regarding not encouraging parents to discriminatorily withhold consent for treatment and the responsibility of the hospital concerning physicians with staff privileges. The important new element is the responsibility of providers to report Infant Doe cases to the State child abuse and neglect agency. This responsibility is within the existing regulatory requirement that recipients of Federal funding not aid or perpetuate the discriminatory action of another person. The analysis is that it aids and perpetuates the discriminatory action of the parents for the hospital to rest upon State law requirements regarding parental consent and fail to undertake the simple, burdenless act of accessing the system provided by State law to overcome wrongful parental actions. The notion of hospitals reporting to the appropriate State agency suspected cases of child abuse and neglect is not at all new. In fact, all States now require physicians to make such reports (although it is not clear whether current practice by hospitals and agencies uniformly considers Infant Does to be neglected children).

In addition, the guidelines do not repeat the suggestion contained in the May 18 Notice regarding the discharge of the infant. Rather, the guidelines state a hospital's responsibility to report suspected Infant Doe cases is not relieved by the discharge of the infant.

4. Responsibilities of State child abuse and neglect agencies.

Although the Office of Human Development Services does not have precise data, it appears that all State child abuse and neglect programs receive Federal funding from HHS under either the child abuse and neglect program or the child welfare services program. These agencies therefore have responsibilities under both section 504 and the program regulations. The guidelines refer to both sets of responsibilities in stating that these agencies may not discriminatorily fail to take action on behalf of Infant Does, and they must, pursuant to programmatic responsibilities, consider the failure to provide adequate medical care to Infant Does to constitute medical neglect. These responsibilities are not out of line with existing State agency authorities. Presently,

38 States specifically refer to medical neglect in their child abuse and neglect laws, and all of the others have statutory language apparently broad enough to include medical neglect. No State child abuse and neglect statute appears to have language restricting jurisdiction in Infant Doe cases.

Conclusion

The Department should issue the guidelines described above, and should solicit comment on them.

Attachments: Tab 1 - Draft Guidelines  
Tab 2 - May 18 Notice to Health Care Providers