

Baby Doe Redux? The Department of Health and Human Services and the Born-Alive Infants Protection Act of 2002: A Cautionary Note on Normative Neonatal Practice

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ABSTRACT. The Born-Alive Infants Protection Act (BAIPA), passed by Congress in 2002, has attracted little publicity. Its purposes were, in part, "to repudiate the flawed notion that a child's entitlement to the protections of the law is dependent on whether that child's mother or others want him or her." Understood as antiabortion rhetoric, the bill raised little concern among physicians at the time of legislative hearings and passed in both Houses by overwhelming majorities, hardly suggesting contentious legislation. After its signing into law, the Neonatal Resuscitation Program (NRP) Steering Committee issued an opinion stating that "[BAIPA] should not in any way affect the approach that physicians currently follow with respect to the extremely premature infant." This interpretation of the law, however, may have been short sighted.

In April 2005, the US Department of Health and Human Services (DHHS) brought life to the BAIPA, announcing: "As a matter of law and policy, [DHHS] will investigate all circumstances where individuals and entities are reported to be withholding medical care from an infant born alive in potential violation of federal statutes." The agency issued instructions to state officials on how the definitional provision within the BAIPA interacts with the Emergency Medical Treatment and Labor Act (EMTALA) and the Child Abuse Prevention and Treatment Act (CAPTA). These interagency memoranda potentially resurrect dormant governmental oversight of newborn-treatment decisions and thus may have influence over normative neonatal practice.

Under the BAIPA, the DHHS interprets EMTALA to protect all "born-alive" infants; hospitals and physicians violating regulatory requirements face agency-sanctioned monetary penalties or a "private right of action by any individual harmed as a direct result." According to its memorandum, the DHHS will investigate allegations of EMTALA violations whenever it finds evidence that a newborn was not provided with at least a medical screening examination under circumstances in which a "prudent layperson observer" could conclude from the infant's "appearance or behavior" that it was "suffering from an emergency medical condition." The memorandum fails to clarify which observers qualify as prudent,

what infant appearance or behavior is relevant, or what defines an emergency medical condition. Because these evaluative criteria are not constrained by reference to relevant standards of medical care, the agency arguably substitutes a nonprofessional's presumed sagacious assessment of survivability for reasonable medical judgment.

Indeed, under a straightforward reading of the instruction, a family member could conceivably trigger an investigation after observing a relative deliver a 20-week fetus who maintains a heartbeat for an hour before its death. Most physicians would not consider this an emergency medical condition and, rather than perform a screening examination, would provide comfort for the newborn and support for the family. The guideline, however, does not state that professional acumen trumps the layperson's observations in these instances; thus, physicians are left unclear about whether screening examinations are required for all newborns regardless of a priori, reasoned considerations of survivability. In this context, the NRP Steering Committee opinion states that "at the time of delivery . . . the medical condition and prognosis of the newly born infant should be assessed. At that point decisions about withholding or discontinuing medical treatment that is considered futile may be considered by . . . providers in conjunction with the parents acting in the best interest of their child." However, most pediatricians skilled in screening and resuscitation are not currently called on to perform this function when the gestational age of a nonviable fetus is reasonably certain before delivery. If under the law screening is now required at any gestational age, professional procedure immediately after previsible births may need modification. More worrisome, threatened aggressive investigations of alleged EMTALA violations at the soft edges of viability, where futility remains a matter of debate, jeopardize the normative ethical practice of offering discretionary palliative care.

The DHHS sent its other instruction to state child protective services agencies responsible for implementing CAPTA regulations; it reiterates the limited situations in which physicians may withhold medical treatment from infants and reemphasizes the local role of "individuals within health care facilities" to notify authorities of suspected infractions. Its real import, however, is insistence on local execution of legal remedies to prevent nontreatment decisions deemed impermissible by the 1984 Baby Doe rules. Because this new directive encourages governmental oversight of treatment decisions involving imperiled newborns, a period of benign regulatory neglect seems to be over. The federal CAPTA rules arguably remove quality-of-life considerations from the decision-making calculus and therefore may conflict with the best-interests paradigm advocated by the American Academy of Pediatrics and NRP.

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How courts will respond to the DHHS interpretation of EMTALA and CAPTA under the BAIPA remains unclear. Federal courts have yet to authoritatively examine alleged EMTALA violations involving newborn treatment decisions at the limits of viability. The Wisconsin Supreme Court has permitted an EMTALA claim to go to trial where physicians allegedly did not screen or resuscitate a 22-week newborn delivered in an emergency department, and a lower appellate court has relied on CAPTA to hold that parents do not possess the right to choose against resuscitating an extremely premature newborn. The Texas Supreme Court recently granted physicians the paternalistic prerogative to resuscitate imperiled newborns without attention to parental preference under a common law doctrine of "emergent circumstances." These judicial decisions undermine the ethical discretion parents are typically afforded in decision-making before and after delivery in these morally complex situations. The DHHS interpretation of the BAIPA may encourage jurisdictional creep of these kinds of pronouncements as the agency seeks to expand legal protections for born-alive infants.

The US Supreme Court has stated that "courts must presume that a legislature says in a statute what it means and means in a statute what it says there"; thus, judges interpret law by analyzing "concrete statutory language, not by reference to abstract notions of generalized legislative intent." The BAIPA indiscriminately defines "born alive" to include an infant "at any stage of development . . . regardless of whether the expulsion or extraction occurs as a result of natural or induced labor, cesarean section, or induced abortion," and it makes no reference to standards of care or best interests, nor does it specifically protect a parent's decision-making authority. Under the law's strict logic, an 18-week miscarried fetus with a detectable heart beat after delivery is entitled to the full protections of the law as determined by "any Act of Congress, or any ruling, regulation, or interpretation of the various administrative bureaus and agencies."

Before concluding that the BAIPA would not affect normative neonatal practice, the NRP Steering Committee should have analyzed the act's actual statutory language and avoided relying heavily on imprecise legislative intent. The BAIPA's congressional sponsors did claim that the law "will not mandate medical treatment where none is currently indicated," but such political rhetoric is often not sufficient to render law innocuous years after separation from its legislative history. Besides, nowhere in the House record does the majority explicitly acknowledge that discretion to decide the fate of imperiled newborns invests in parents, in consultation with physicians; indeed, the bill's stated purpose was to repudiate that notion. At best, legislators recognized that physicians disagree about the efficacy of resuscitating at the limits of viability, and therefore the current standard of care permits doctors to deem resuscitation a futile endeavor. However, judges may resist characterizing resuscitation as futile, given its poor analytical fit, and substantial public-policy concerns regarding discrimination against future disabled individuals could easily tip a court to preserve incipient, at least, physiologic life under the BAIPA's all-encompassing definition of born alive. *Pediatrics* 2005;116:e576–e585. URL: www.pediatrics.org/cgi/doi/10.1542/peds.2005-1590; *decision-making, death and dying, ethics, extremely preterm infants, health policy*.

ABBREVIATIONS. BAIPA, Born-Alive Infants Protection Act; DHHS, US Department of Health and Human Services; EMTALA,

Emergency Medical Treatment and Labor Act; CAPTA, Child Abuse Prevention and Treatment Act; AAP, American Academy of Pediatrics; NRP, Neonatal Resuscitation Program; CMS, Centers for Medicare and Medicaid Services; CRP, child protective services.

INTRODUCTION

On April 22 2005, US Department of Health and Human Services (DHHS) Secretary Mike Leavitt announced "As a matter of law and policy, [DHHS] will investigate all circumstances where individuals and entities are reported to be withholding medical care from an infant born alive in potential violation of federal statutes for which we are responsible."¹ He stated that his agency "would take proactive steps to educate state officials, health care providers, hospitals, and child protection agencies about their obligations to born-alive infants."² In making this proclamation, Secretary Leavitt derived his authority from Public Law 107–207 (H.R. 2175), the so-called Born-Alive Infants Protection Act (BAIPA), which amends Title 1 of the US Code as follows:

(a) In determining the meaning of any Act of Congress, or any ruling, regulation, or interpretation of the various administrative bureaus and agencies of the United States, the words "person", "human being", "child", and "individual", shall include every infant member of the species homo sapiens who is born alive at any stage of development.

(b) As used in this section, the term "born alive" . . . , means the complete expulsion or extraction from his or her mother of that member, at any stage of development, who after such expulsion or extraction breathes or has a beating heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, regardless of whether the umbilical cord has been cut, and regardless of whether the expulsion or extraction occurs as a result of natural or induced labor, cesarean section, or induced abortion.³

Two of the relevant federal statutes for which the DHHS is administratively responsible and interact with Public Law 107-207 are the Emergency Medical Treatment and Labor Act (EMTALA) and the Child Abuse Prevention and Treatment Act (CAPTA). Sanctions for violating the "responsibilities of hospitals to protect the rights of all individuals"⁴ may arise from expanded enforcement of the federal regulations supporting these laws.

Reminiscent of the Reagan-administration's policies after congressional passage of the so-called Baby Doe law⁵ in 1984, the current administration's resurrection of recently quiescent oversight of the treatment of imperiled newborns agitates the legal fault line that physicians walk along when caring for these infants.⁶ This commentary analyzes the impact that the BAIPA, as interpreted by the current administration, may have on normative perinatal and neonatal medical practice.

Public Law 107-207

Political History

The BAIPA of 2002 was, in some measure, a reaction to the Supreme Court's earlier majority decision in *Stenberg v Carhart* overturning a Nebraska law that outlawed partial-birth abortion.⁷ As introduced in House Report 107-186, the purposes of the bill were, in part:

(1) to repudiate the flawed notion that a child's entitlement to the protections of the law is dependent on whether that child's mother or others want him or her;

(2) to repudiate the flawed notion that the right to an abortion means the right to a dead baby, regardless of where the killing takes place.⁸

Understood initially as a certain antiabortion rhetorical gesture, this bill raised only modest public concern among physicians with respect to its potential impact on medical practice at the time of congressional hearings. However, neonatologists Gordon Avery and F. Sessions Cole conveyed their anxiety formally in writing to House committee members that the legislation might substantially "interfere with the agonizing, painful, and personal decisions that must be left to parents in consultation with their physicians."⁹ In addition, because the law would "deny parents and deny doctors the right to make decisions about premature infants," Congresswoman Nancy Johnson, a Republican from Connecticut, argued against an early version of the bill in the 106th Congress.¹⁰

In the summer of 2002, lingering concerns about the legislation's detrimental impact on neonatal treatment decision-making presumably receded because the bill passed in both Houses by voice vote, hardly suggesting a contentious piece of legislation. After President Bush signed it into law, the American Academy of Pediatrics (AAP) Neonatal Resuscitation Program (NRP) Steering Committee issued an opinion stating that the act

[S]hould not in any way affect the approach that physicians currently follow with respect to the extremely premature infant. Physicians should discuss treatment options with parents, preferably before the birth of the infant. Treatment plans should be based on currently available information and outcomes. . . . Those newly born infants who are deemed appropriate to not resuscitate or to have medical support withdrawn should be treated with dignity and respect, and provided with "comfort care" measures.¹¹

Since its passage, the act has hardly attracted any publicity despite a principle legislative architect proclaiming its passage as "truly momentous."¹² As late as May 2005, general interest within the health care professions for this law has remained minimal. A National Library of Medicine electronic database search of its official title produced only 3 "hits": one was the aforementioned AAP opinion published in *Pediatrics* in 2003, another was a 2003 neonatal nursing review article, and the third was a prelegislative 2000 advocacy essay in *The Human Life Review*.¹³ Thus, in terms of influencing public policy, the law has laid dormant, lending support to the comments of Congressman Melvin Watt, 1 of 2 House members who voted against the bill while it was still in committee: "At its best, the bill does nothing, and many of the supporters of this bill say that it does nothing. It does not change existing law. It does nothing."¹⁴

Symbolic or Substantive Law?

Could the BAIPA be truly momentous and still do nothing? If, as several House minority members insisted, it is the "symbolic bill its proponents contend,"¹⁵ and will not "substitute the judgement [sic] of Congress for the judgement [sic] of a qualified health

care provider,"¹⁶ how then do we interpret Secretary Leavitt's April 22, 2005, memoranda to state agencies clarifying its impact on EMTALA and CAPTA? These instructions suggest that the administration understands the law to enunciate substantive protections for a class of "individuals" who heretofore may have fallen beneath the regulatory radar.¹⁷

EMTALA

EMTALA, the so-called antidumping law, places potential provider obligations on hospitals and physicians when presented with an "individual" who may have an emergency medical condition regardless of the individual's ability to pay.¹⁸ Because individuals include all "born-alive" infants as defined by Public Law 107-207, the Centers for Medicare and Medicaid Services (CMS), a subunit of the DHHS, created its "Guidance on the Interaction of the Born-Alive Infants Protection Act and EMTALA." The interagency memorandum prefaces its instruction with the following:

It has recently come to the agency's attention that there may be occasions where, in hospitals, an infant may be born alive within the meaning of the definition added to the U.S. Code by [the act], but where hospitals have failed to comply with the requirements of EMTALA.¹⁹

The guideline then sketches out examples in which a hospital or physician failing to comply with regulatory requirements could be subject to an agency-sanctioned monetary penalty or a "private right of action by any individual harmed as a direct result."²⁰ The guideline provides that "the labor and delivery department of a hospital could meet the definition of dedicated emergency department" but also asserts that such a presumption is not necessary for EMTALA to apply:

[W]ere an infant to be born alive elsewhere on the hospital's campus (i.e., not in the hospital's dedicated emergency department) and a prudent layperson observer concluded, based on the born-alive infant's appearance or behavior, that the born-alive infant were suffering from an emergency medical condition . . . , the hospital and its medical staff would be required to perform a medical screening examination on that born-alive infant. . . . If . . . determined that the born-alive infant were suffering from an emergency medical condition, there would then arise an obligation to admit the infant, or to comply with either the stabilization requirement or the transfer requirement, or risk a finding of an EMTALA violation.²¹

The guideline further warns that although admitted patients are not subject to EMTALA protections, "it would be a violation . . . to admit an individual to the hospital in a bad faith attempt to evade [its] obligations."²² Arguably then, the admission of a marginally viable born-alive infant only to let her die without ongoing resuscitative efforts could be regarded as a sham and might trigger a "bad-faith" violation of the law.

The CMS memorandum is remarkable as much for what is not written as for what is. Taken at face value, it would seem that the DHHS will now begin to investigate allegations of EMTALA violations whenever it finds presumptively credible evidence that a born-alive infant was not provided with at least a medical screening examination under circumstances in which a "prudent layperson observer"

could conclude that the infant was “suffering from an emergency medical condition.” Unfortunately, the memorandum itself provides no illumination on which lay observers would qualify as “prudent,” what infant “appearance or behavior” is relevant, or what defines an “emergency medical condition.” This absence of clarification leaves far too much interpretive freedom for agency investigators, let alone lay observers. More importantly, the memorandum, as written, fails to constrain these evaluative criteria by reference to relevant standards of medical care.

Without such an explicit, clinically relevant orientation, the guideline seems to substitute a nonprofessional’s presumed sagacious assessment of survivability for reasonable medical judgment. Indeed, under a straightforward reading of the guideline, a concerned adult family member could conceivably trigger an EMTALA investigation after observing his or her relation deliver a 21-week fetus in a labor room who moves his legs after expulsion or who has a heartbeat for an hour after cord separation before his death. To this lay observer, the muscle movement or heartbeat clearly could qualify as behavior that suggests the presence of an “emergency medical condition,” as defined in the most recent Code of Federal Regulations:

A medical condition manifesting itself by acute symptoms of sufficient severity such that the absence of immediate medical attention could reasonably be expected to result in—(i) Placing the health of the individual (or, with respect to a pregnant woman or her unborn child) in serious jeopardy.²³

Of course, most physicians would not consider this an emergency medical condition but rather a hopeless one and would only proceed with providing comfort care to the newborn and social support for the family. In this context, the NRP Steering Committee opinion sensitively recommends:

At the time of delivery . . . the medical condition and prognosis of the newly born infant should be assessed. At that point decisions about withholding or discontinuing medical treatment that is considered futile may be considered by . . . providers in conjunction with the parents acting in the best interest of their child.²⁴

However, most pediatricians skilled in screening (and resuscitation) are not currently called on to perform this function when previable gestational age (eg, 21 weeks) is reasonably certain before delivery, because a screening examination that reveals physiologic signs of life is devoid of therapeutic and prognostic significance. Does such professional acumen trump a prudent layperson’s observations? The CMS guideline does not provide an answer. If the absence of professional medical judgment disqualifies a layperson from a consideration of “prudence,” then the administration’s guideline should have stated that clearly. Instead, physicians are left unclear whether they must perform screening medical examinations on all born-alive infants regardless of a priori, reasoned considerations of survivability.

If a screening medical examination is mandated by EMTALA under Public Law 107-207, it still remains unclear what purposes that procedural burden serves in clear cases of nonsurvivability. If providers must now screen all previable born-alive infants or

any newborn with a known lethal anomaly for the purposes of confirming the futility of medical intervention, such added ritual risks becoming nothing more than a professional charade, contributing no procedural or substantive protection to an unfortunately doomed newborn. More ethically worrisome, if physicians are now required to screen newborns in circumstances under which prospective parents have already chosen comfort care at the soft margins of viability (at which futility is clearly a matter of therapeutic debate), providers may feel compelled to override such personal choices at the moment of screening given a perceived threat of being cited for an EMTALA violation from the DHHS. Worse still, aggressive agency investigations and/or EMTALA enforcement could even jeopardize the normative ethical practice of offering parents discretionary palliative care at the soft margins of viability in the first place. As such, it seems that rather than educating state officials, hospitals, and health care providers “about their obligations to born-alive infants,” the DHHS has complicated and confused the duties of perinatal and neonatal care providers under EMTALA.

How courts will respond to the agency’s interpretation of EMTALA in light of Public Law 107-207 also remains unclear. EMTALA has a notable interpretive history within the federal circuit, exemplified by the expansive 1994 opinion *In re Baby K*, which was initially understood by many to require an ongoing duty to provide stabilizing treatment under EMTALA to an individual with an emergency medical condition even when a responsible physician determined that such treatment was not medically or ethically appropriate.²⁵ Subsequently, the fourth circuit and other federal courts have restricted the reach of *Baby K*, recognizing that the law does not create a private right to demand that physicians and hospitals provide ongoing medical stabilization and/or treatment of indefinite duration.²⁶ To date, the federal circuit has not had occasion to address an EMTALA action involving facts that pertain to the resuscitation of a newborn at the edge of viability.²⁷

State courts, however, have recently had opportunities to examine EMTALA in contexts specific to the provision of care to born-alive extremely premature infants. In *Burks v St Joseph’s Hospital*, the Supreme Court of Wisconsin allowed a plaintiff’s claim alleging a violation of EMTALA to go forward, under facts where physicians did not resuscitate her 200-g, roughly 22-week newborn and where a neonatologist filed an affidavit stating “resuscitation was not medically indicated for [this] fetus and in fact is medically inappropriate for any fetus weighing 200 g.”²⁸ After delivery, the infant was reportedly provided with comfort care and had a heart beat for approximately 2 hours before expiring. It is important to note that the reviewing court did not reach the merits of the EMTALA claim, but the holding at least opens the door for future aggrieved parties to seek judicial relief for failure to screen and resuscitate previable newborns under EMTALA. Public Law 107-207 as interpreted by the DHHS arguably strengthens the claim to legal remedy.

Additionally, in 2004 a Wisconsin state appellate

court affirmed a decision dismissing a plaintiff's claim that the hospital had violated EMTALA in failing to screen or stabilize her 23-week newborn after delivery in an obstetric suite.²⁹ In reaching its conclusion, the Wisconsin Court relied on a federal opinion that read the EMTALA screening requirement to technically apply only to individuals who "come to the emergency department."³⁰ Importantly, however, in choosing to "hold [the hospital] responsible for the plain language of [EMTALA] and not subsequent revisions of the rule," the state court acknowledged that the DHHS had since interpreted the screening requirement to apply to an individual who "has presented on hospital property," thus leaving open the possibility of a contrary outcome in a future case with similar facts.³¹ Certainly the 2005 CMS guideline demonstrates that the DHHS no longer considers the in-hospital birthplace of a born-alive infant a potential legal barrier to running afoul of EMTALA's screening requirement.

CAPTA

CAPTA ties federal-to-state grant money to the local implementation of regulatory procedures for responding to allegations of infant and child abuse and neglect; to secure funding, states must tailor their child protection laws to comport with federal standards.³² The 1984 "Baby Doe" amendments to CAPTA broadened the requirements for states to receive federal money by requiring local child protective services (CPS) to investigate and prevent the withholding of "medically indicated treatment" from disabled infants less than 1 year of age with life-threatening conditions. The amendments limit the circumstances under which a physician may withhold treatment from an infant to 5 conditions: (1) the infant is chronically and irreversibly comatose; (2) the treatment would merely prolong dying; (3) the treatment would not be effective in ameliorating or correcting all of the infant's life-threatening conditions; (4) the treatment would be futile in terms of survival; and (5) the treatment would be virtually futile in terms of survival and the treatment itself under such circumstances would be inhumane.³³ Regarding these restrictions, one commentator recently stated:

The plain language of the Baby Doe rules . . . reflects the Reagan-Administration view that judges, clinicians, and parents must never withdraw or withhold medication, nutrition, or hydration from infants . . . , federal law [does] not permit federally funded hospitals to starve infants or use quality-of-life consideration in deciding what interventions [are] futile or virtually futile.³⁴

Nevertheless, many physicians believe ethical duty requires frank discussions about quality-of-life considerations when reviewing treatment options with parents facing the imminent delivery or continued care of a marginally viable fetus. Thus, the federal rules' persistence in the law for more than 20 years remains the source of much psychological consternation for practicing physicians, because they remain strikingly detached from normative perinatal and neonatal practice.³⁵

After initial passage of the 1984 CAPTA amend-

ments, the DHHS promulgated regulations and interpretive guidelines that clarified the law and the procedures that states were required to implement to ensure that neonatal nontreatment decisions were receiving adequate governmental oversight.³⁶ Today, primary responsibility for ensuring that physicians and hospitals are not withholding medically indicated treatment from infants still rests with local CPS agencies, although enforcement of the federal regulations remains extremely rare. Presumably, during much of the 1990s the then-administration's political leanings directed interest away from forcing states to vigorously uphold local institutional compliance with federal regulations. The historical dearth of federal sanctions against states for failing to prevent purported Baby Doe violations, however, has not dissuaded the current administration from resuscitating CAPTA's regulatory life. On April 22, 2005, the Administration for Children and Families, a subunit of the DHHS, sent its interagency "program instruction" to state CPS agencies responsible for implementing CAPTA and its supporting regulations. The memorandum states:

[T]he purpose of [Public Law 107-207] was to reaffirm the legal principle that infants who are born alive, at any stage of development . . . are persons entitled to the protections of the law.³⁷

It then specifically reiterates to local administrators the limited situations under which physicians may permissibly withhold medical treatment from infants and reemphasizes the local role of "individuals within health care facilities" to promptly notify CPS of suspected violations. Finally, it adds that states must ensure:

[t]he authority for State Child Protective Services to pursue, and the *actual pursuit* of, any legal remedies that may be necessary to prevent the withholding of medically indicated treatment from disabled infants with life-threatening conditions.³⁸

Thus, the real importance of this memorandum seems to be a renewed emphasis on the local execution of legal remedies by state officials to prevent nontreatment decisions deemed impermissible by the Baby Doe rules.

As such, a period of benign regulatory neglect seems to be over. Indeed, the implementation of this new directive suggests an intrusive future in which governmental oversight of treatment decisions involving imperiled newborns returns to hospital obstetric and nursery suites. However, even assuming the current administration's threat to remove federal CAPTA funding is real, serious obstacles face CPS agencies in mounting investigations for purported CAPTA violations. First, state CPS agencies are already notoriously understaffed and underfinanced; diverting resources to support these endeavors presumes local infrastructural capacity that simply may not exist. Second, DHHS regulations organize investigative power in a remarkably passive manner. Hospitals designate the individuals "responsible for reporting cases of medical neglect and require only minimal contact between the designated reporter and the state agency," thereby effectively eliminating

external pressure to disclose nontreatment decisions.³⁹ As a practical matter, because most nontreatment decisions of newborns involving prohibited quality-of-life considerations are made consensually by parents and physicians, little, if any, internal institutional incentive exists to disclose these decisions to outside authorities. Concerns about confidentiality and privacy rights may also hinder case-specific reporting in these situations. Ultimately, because CAPTA provides only financial incentive for states and creates no direct enforcement power, the law and its supporting regulations remain a clumsy vehicle for controlling bedside decision-making for the imperiled newborn.⁴⁰

Yet, there are judicial indications that CAPTA could play a greater role in regulating newborn treatment choices. In *Montalvo v Borkovec*, the parents of a resuscitated 23-week infant alleged that the physicians and hospital were negligent in failing to inform them about the risks of complications when treating an extremely premature newborn.⁴¹ The deciding state court of appeals stated:

First, requiring the informed consent process here presumes that a right to decide not to resuscitate the newly born child . . . actually existed. This premise is faulty.⁴²

In reaching this conclusion, the court relied, in part, on its interpretation of CAPTA obligations: "Under . . . federal statutory law, [the parents] did not have the right to withhold or withdraw immediate postnatal care from him."⁴³ Although this opinion has uncertain value as precedent outside of its state jurisdiction, it is noteworthy as judicial validation of CAPTA's authority to severely limit the situations in which physicians may permissibly withhold medical treatment.

Without relying on CAPTA but nevertheless acknowledging that "the federal 'Baby Doe' regulations are part of Texas law and forbid any denial of medical care based on quality-of-life considerations," the Texas Supreme Court recently granted physicians the paternalistic prerogative to unilaterally resuscitate marginally viable newborns under a common-law doctrine of "emergent circumstances."⁴⁴ Although widely criticized by physicians and bioethicists, the Texas decision discounts the importance of obtaining parental consent in medical crises involving newborns and, thus, may also have influence over normative neonatal resuscitative practice in delivery situations in which futility remains debatable.⁴⁵ Certainly additional jurisdictional creep of the legal pronouncements in Wisconsin and Texas seems plausible with an Administration that seeks to expand protections for born-alive infants under Public Law 107-207. Regardless, it is clear that these state decisions directly challenge the ethical discretion that the AAP affords parents to choose palliative care at the margins of newborn viability both before and after delivery.

Legislative Intent Behind the BAIPA

Taken together, the DHHS memoranda interpreting the BAIPA suggest an attempt to re-exert regulatory control over discretionary medical decision-

making involving an imperiled newborn through threat of governmental sanction. In concluding that the law should not affect normative neonatal practice, the NRP Steering Committee relied heavily on perceived legislative intent as documented in the House report accompanying the act.⁴⁶ The congressional record does place doubt on broad administrative authority under the statute to control medical judgment at the bedside of an imperiled born-alive infant. The law's sponsors stated:

H.R. 2175 draws a bright line between the right to abortion . . . and infanticide, or the killing or criminal neglect of completely born children. . . . If, for example, an infant is born alive at a Federal hospital as a result of a failed abortion attempt, this bill makes clear that the attending physicians and other medical professionals should treat the infant *just as they would treat a similarly situated infant who was born as a result of natural labor* [emphasis added].⁴⁷

Thus, Congress would seem to allow context-specific considerations when physicians are faced with a born-alive infant; the key inquiry is how do physicians, not prudent lay observers, "treat a similarly situated infant who was born as a result of natural labor?" If such a similarly situated infant would receive comfort care alone, then arguably that is all that is required by the law.

Of course, Secretary Leavitt and the current administration may not have simply sought to ensure that born-alive infants of failed abortions or marginal viability would receive only comfort care in the future when the DHHS announced its new investigative focus in April 2005. Yet, the law's sponsors acknowledged:

The reason [that this statute does] not define a live birth as dependent on the infant's gestational age is fairly obvious. Many infants are born alive at 20 to 22 weeks and survive for hours, although their lung capacity typically does not permit sustained survival. Under the prevailing standards of medical care, such infants are understood to be born-alive persons and are treated as such, although they may only live for a short time. They are, for example, treated humanely, given comfort care, and issued a death certificate.⁴⁸

Besides recognizing that certain born-alive newborns simply cannot survive after delivery because of extreme prematurity, the Majority also affirmatively emphasized that the bill would lack practical impact on physician decision-making to assuage fears that professional autonomy would be affected adversely:

H.R. 2175 will not mandate medical treatment where none is currently indicated. Although there is a debate about whether or not to aggressively treat premature infants below a certain birth weight, this is a dispute about medical efficacy, not regarding the legal status of the patient. . . . Medical authorities who argue that treatment below a given birth weight is futile are not arguing that these low-birth weight infants are non-persons, only that providing treatment in those circumstances is not warranted under the applicable standard of care. H.R. 2175 would not affect the applicable standard of care, but would only insure that all born-alive infants-regardless of their age and regardless of the circumstances of their birth-are treated as persons for purposes of Federal law.⁴⁹

The House Minority also qualified their support for the bill based on assurances that the bill "should not affect the decisions of families and neonatologists."⁵⁰ Representative Nadler, a Democrat from

New York and a vocal critic of the bill, submitted the following statement for the record:

I do not want to trivialize the concerns of neonatologists, but I was gratified by the testimony that we received from the majority of witnesses at our Subcommittee hearing on this legislation which indicated that, while an infant may be considered "born alive" under this legislation, it would not in any way substitute the medical judgment of Congress for the judgment of doctors on the scene, or interfere with the painful decisions that families must make under the most difficult of circumstances. We must respect families and not have the big hand of government make their worst moments even more unbearable. I trust that the sponsors of this legislation are in agreement.⁵¹

Expert testimony relied on by both political parties came chiefly from an emeritus professor of obstetrics, Dr Watson Bowes, who was also the former chairman of the American College of Obstetrics and Gynecology's Committee on Ethics. He testified:

[T]his definition of live birth does not restrict a physician's prerogative to recommend that medical care regarded as futile be withdrawn or withheld. It is important to keep in mind that this bill deals solely with the criteria that define whether an infant is alive at the time of birth. It does not legislate how physicians and parents may deal with the decision about withholding or discontinuing medical or surgical treatment that is considered futile in the care of the infant.⁵²

Collectively, these legislative statements support an analysis that permits nontreatment decisions at the margins of viability but, strictly speaking, rendered only in terms of futility. Thus, the congressional history behind Public Law 107-207 does superficially support the NRP Steering Committee's opinion, but only with critical qualification.

Statutory Construction, Legislative Intent, and the Courts

The statements of politicians and expert testimony recorded within congressional hearings are often not sufficient to render law innocuous years after a statute has separated from its legislative history. Statutory construction is a technical skill subject to competing interpreting canons within the judiciary; indeed, scholarly legal textbooks are devoted to the art, and there is no dearth of lawyerly controversy when it comes to the proper interpretation of statutory law.⁵³ On the one hand, the US Supreme Court has stated that "courts must presume that a legislature says in a statute what it means and means in a statute what it says there."⁵⁴ Thus, many judges first interpret law by analyzing concrete statutory language, not by reference to abstract notions of generalized legislative intent.

We start our search for the meaning of the words Congress wrote with an appraisal of the statutory text and structure, mindful that if the plain language of the statute points unerringly in a single direction, an inquiring court should look no further . . . although legislative purpose can shed light on congressional intent where Congress has blown an uncertain trumpet, *it cannot serve* as the baseline for statutory construction [emphasis added].⁵⁵

On the other hand, courts also commonly recognize "[T]he language of a statute should not be given a literal meaning if doing so would result in absurd consequences which the [electorate] did not intend." Thus, "the intent prevails over the letter, and the

letter will, if possible, be so read as to conform to the spirit of the act. . . . [W]e do not construe statutes in isolation, but rather read every statute with reference to the entire scheme of law which it is part so that the whole may be harmonized and retain effectiveness."⁵⁶

Regarding the actual language of the BAIPA, there is no question that the words are indiscriminately broad: "born alive" includes an infant "at any stage of development . . . regardless of whether the expulsion or extraction occurs as a result of natural or induced labor, cesarean section, or induced abortion."⁵⁷ More importantly, because "courts have an obligation to refrain from embellishing statutes by inserting language that Congress opted to omit,"⁵⁸ it is noteworthy that the law avoids any reference to standards of care or best interests and does not specifically protect a parent's decision-making authority after delivery. Under its strict logic, an 18-week miscarried fetus with a detectable heart beat after delivery is entitled to the full protections of the law as determined by "any Act of Congress, or any ruling, regulation, or interpretation of the various administrative bureaus and agencies."⁵⁹ Obviously, reading the full protections of the law to require screening and/or resuscitation of a known nonviable born-alive infant would lead to absurd results, and given the expressed legislative intent to ensure humane treatment and comfort care for infants clearly born before viability, judges are unlikely to interpret the law to force such a useless practice.

However, at the soft edges of viability, where futility remains debatable even within the medical profession,⁶⁰ matters become far more problematic. First, nowhere in the House report does the Majority acknowledge without qualification that discretion to decide the fate of imperiled newborns invests in parents, in consultation with physicians; indeed, one of the bill's stated purposes was "to repudiate the flawed notion that a child's entitlement to the protections of the law is dependent on whether that child's mother or others want him or her."⁶¹ It is hard to reconcile this legislative statement with the position that parents maintain the right to refuse life-sustaining treatment in a potentially salvageable newborn. The Majority's conspicuous failure to recognize a primary parental role in these after-birth life-or-death decisions implies that physicians alone may legitimately argue about when treatment is futile or medically inappropriate when faced with an imperiled newborn; because physicians currently disagree about the efficacy of resuscitating at the limits of viability, Congress seems to accept that the current "standard of care" allows resuscitation to be deemed a futile endeavor.

However, categorizing as futile the decision to forego resuscitation or treatment of a borderline-viable newborn is, at best, a stretch. Numerous medical and bioethical commentators have long sought to discard using the term futility in these situations, because it is a terrible analytical fit.⁶² When faced with a marginally viable newborn, physicians (and parents) must evaluate the statistical probability of survival and the statistical risk of serious handicap as a result of survival. Interpreting the meaning of those

statistics is inherently subjective, and judging the risk/benefit ratio in these situations is nothing that physicians, by virtue of their medical training, have appropriate expertise in, because such assessments evaluate, by definition, future quality of life. A 40% chance of survival even with an 80% chance of significant handicap may seem entirely acceptable to some prospective parents despite many physicians feeling otherwise. Treating physicians bear no long-term responsibility for the care of potentially serious handicapped infants after their discharge, and so most believe that they are ethically required to invite and include parents in this value-based decision-making process about the family's future. Such interpersonal moral inquiry into later life prospects has no clear analytic relationship to considerations of futility, as the *Montalvo* court cautioned:

This determination could vary greatly based on the parents' beliefs. One set of parents may view a particular disability as "worse than death," while another set of parents would not. Such a process, not unreasonably, has kaleidoscopic, unending implications.⁶³

Thus, when a parent and physician decide not to treat a marginally viable newborn, they typically are not basing the decision on an assumption that any proposed intervention will be futile in rescuing the newborn. If, in respecting the medical standard of care, Congress only sought to avoid meddling with a technical medical determination of futility, Public Law 107-207 arguably protects little, if any, parental discretion at the limits of viability.

Indeed, in actual contested cases involving newborn treatment decisions pitting parent versus physician or government versus physician/parent, a reviewing court will not likely duck behind a supposedly protected medical standard of care to avoid wrestling with competing conceptions of value in life. Few judges could logically approve the foregoing of screening and resuscitation of a born-alive infant who has a 30% chance of survival with significant likelihood of serious handicap at 23 weeks' gestation based solely on considerations of futility. Courts may have other analytic means available to allow nontreatment decisions, but even the ethically favored "best-interests" standard may not safeguard physician/parental discretion in situations for which a judge narrowly compares the risk of a future damaged newborn life on the one hand and the "interest" in no life on the other:

[T]here is a presumption that continued life is in the best interests of a patient. In the absence of proof of a persistent vegetative state, our courts have never decided it is in the best interests of a patient to withhold or withdraw life-sustaining medical care.⁶⁴

Concerns about future poor quality of life remain somewhat speculative in these situations, because accuracy is lacking in predicting long-term cognitive outcomes during the first few hours and days after the birth of a marginally viable newborn (absent a devastating injury); thus, "it is impossible for the courts to calculate the relative benefits of an impaired life versus no life at all."⁶⁵ Substantial public-policy concerns regarding discrimination against future disabled individuals alone could tip a court

against physician/parental discretion when incipient, at least, physiologic life hangs in the balance, as the trial judge in the *Montalvo* case emphasized:

What the doctors did was save this child's life, and I understand the legal position of the parents is that was a decision they should make, but . . . Protection of children is something that the community has an interest. . . . We simply can't say that the possibility that this child could be disabled or even the probability if it is that strong is sufficient to withhold life-saving measures and decide this child does not deserve to live.⁶⁶

In sum, given (1) the inherent limitations of futility analysis, (2) the lack of clear legislative intent to protect anything more than futility assessments as a standard of care within the history of Public Law 107-207, (3) substantial public-policy concerns regarding discrimination of disabled persons, (4) the states' general interest in preserving life, and (5) the inconsistent and sporadic judicial pronouncements that inform this complex issue, the 2003 NRP Steering Committee opinion dismissing the potential impact of the BAIPA seems rather short sighted. At a minimum, before formulating an opinion, the committee should have paid closer attention to the actual sparse, statutory language within the law and been much more mindful of the dynamic, somewhat unpredictable judicial art of statutory interpretation:

[L]egislative intent is what a legislature as a whole had in mind when it passed a particular statute . . . when [statutory] language is ambiguous or unclear, courts try to glean the legislative intent behind words by looking at legislative interpretations (for instance, reports issued by legislative committees) which were relied on by legislators when voting on the statute. Statutes are often ambiguous enough to support more than one interpretation, and the material reflecting legislative intent is frequently sparse. This leaves courts free to interpret statutes according to their own predilections.⁶⁷

Indeed, it is unfortunate that more physicians did not insist on protection for parental decision-making at the margins of viability within the statutory language of the act itself at the time of congressional deliberations. The expert medical testimony of Dr Bowes before the House Committee is entirely suspect, because his assurances about professional and parental autonomy are couched only in terms of futility. Moreover, he is not a judge, lawyer, or legislator and has no real standing to declare how administrative officials and courts of law should interpret statutory language containing technical definitional provisions. As demonstrated by the *Montalvo* and *Miller* opinions, public-policy concerns alone can easily trump speculative quality-of-life considerations when courts face a live-born infant at the limits of viability. A future judge provided with an opportunity to interpret Public Law 107-207 could certainly find the necessary support to further narrow the scope of permissible discretionary decision-making, particularly when the statute itself seems to point "unerringly in a single direction."

Space permits only passing reference to a related, final concern regarding the unknowable implications of the BAIPA, insofar as every federal law and regulation with the words "person," "human being," "child," and "individual" is affected by it. In their dissenting view, the 2 House Judiciary Committee

members that voted against the bill aptly admonished:

[T]his bill has not been studied in a responsible way . . . this bill would amend some 15 000 provisions of the U.S. Code and 57 000 provisions of the Code of Federal Regulations. . . . Changing the definition of the terms "person," "human being," "child," and "individual" . . . carries an enormous risk of unintended consequences . . . those changes might impose new enforceable duties on State, local, and tribal governments or the private sector.⁶⁸

CONCLUSIONS

The topic of decision-making for the imperiled newborn is cluttered with thousands of commentaries from lawyers, physicians, and ethicists, all advocates in one form or another, who address the utility of legal mechanisms to control the complex process of providing suitable care for these born-alive infants. Indeed, the number of articles on this subject matter rivals the number of newborns potentially affected by such decisions in any given year. Yet, despite 30 years' construction of a paper mountain of sometimes well-reasoned and thoughtful discussion on the topic, one prominent bioethicist has as recently as 2004 called the issue, in America, "intractable."⁶⁹ In 1990, the editors of Harvard Law Review published a comprehensive ethical and legal analysis on the matter of neonatal treatment decisions along with specific proposals on how to improve on past policy mistakes. The authors' opening comments succinctly captured the essential features of the debate then.

The birth of a severely handicapped or premature child thus forces society to choose between competing visions of what gives human life value and to determine the role of modern medical technology in that vision. Currently, decisions to withhold treatment from severely handicapped and premature infants are controlled by federal law; however, the federal standard has proved inadequate to address the complex issues surrounding such decisions. The controversy demands a more effective resolution.⁷⁰

Fifteen years later, in 2005, the governing federal standards remain in place and the editors' conclusion remains accurate. Now, with the DHHS issuing 2 instructional directives to state agencies providing educational guidance on the impact of Public Law 107-207 on EMTALA and CAPTA, continued professional reliance on past regulatory inattentiveness seems especially risky.

Nevertheless, the striking incongruity between federally derived legal doctrine and normative medical practice should give all policy makers and judges interested in this topic reason for careful reflection before proceeding with political rhetoric or expansive interpretations of narrowly construed law. Given the deep moral and emotional turmoil that surrounds marginal newborn medical decision-making, it should come as no surprise that professional adherence to federal policy remains a fiction in the United States; legislating that human life is sacred and is to be preserved in all its forms (absent futility) simply ignores a more complicated set of psychological and sociological motivations for the average individual when thinking about what gives human life value. Of this complexity physicians are keenly

aware. It behooves our state and federal officials, as the representatives of a diverse collection of culturally committed citizens, to probe deeper into the practical, actual considerations that inform treatment decisions affecting an imperiled newborn before threatening to use the strong arm of the law to force a polarizing moralistic agenda on the citizenry.

If Public-Law 107-207 ends up, as a practical matter, only guaranteeing that all unfortunate, previable newborns are treated "humanely" and given appropriate palliative care, we might applaud its effect. To the extent that born-alive infants have been treated without dignity or inhumanely, as was testified to in the House hearings, the medical profession should feel ashamed.⁷¹ Placing a doomed newborn unwrapped and alone in a storage room to die is morally and ethically appalling; however, such cases are exceedingly rare, and a law need not be frivolously crafted to encourage this modicum of decent behavior on the medical profession's behalf.

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