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Mixed Blessings: Intensive Care for Newborns A Report Card for Congress After the Baby Doe Legislation (Review of J. Guillemin & L. Holmstrom: Mixed Blessings: Intensive Care for Newborns)

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Mixed Blessings: Intensive Care for Newborns—A Report Card for Congress After the Baby Doe Legislation

By Jeanne Harley Guillemin & Lynda Lytle Holmstrom. New York: Oxford University Press. 1986. Pp. x, 317.

> *No matter where you draw the line, you're going to be wrong part of the time. In general the goal is to produce neurologically intact babies. . . . [But] among some you let go, some would have turned out okay. And among some you save, there will be "gorks". . . .*[1]

I. INTRODUCTION

Mixed Blessings is a technological and sociological case study of how a particular Level III[2] neonatal intensive care unit (NICU) functions. Guillemin and Holmstrom objectively observe the critical roles of various professionals, unit staff members, and parents in the complex decision-making process which takes place when a newborn suffers from the difficulties that make a Level III nursery necessary. They also explain the state-of-the-art caregiving process at Northeast Pediatric—the pseudonym given to the NICU which the authors analyze—that saves the lives of younger and more critically ill newborns every day. In addition, the authors compare more generally fifteen NICUs in the United States, which in turn are compared to NICUs in several foreign countries. Finally, the authors conclude by making policy recommendations for improvement at the NICU, hospital administration, and government regulatory levels.

To explain the working relationships among the NICU staff, the authors use excellent examples, comments, and dialogue among the participants. The authors do not overemphasize the

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1. J. GUILLEMIN & L. HOLMSTROM, MIXED BLESSINGS: INTENSIVE CARE FOR NEWBORNS 129 (1986) (comment by an attending physician).

2. The authors do not explain the difference between "Level III" nurseries and other "levels" of neonatal care. They do indicate that the three levels arose "during the early development of NICU's in the 1960s and 1970s." *Id.* at 90. "The Level III unit was intended to occupy the apex of a three-tiered system serving infants of high, medium, and minimal medical need." *Id.*

technical aspects of newborn diseases, but do explain in simple terms the most typical medical problems suffered by newborns. In addition, an easy-to-understand glossary of medical terms is included.

Section II of this Note will review the basic topics and themes addressed by the authors in *Mixed Blessings*. Section III will then discuss what role the authors' objective observations might play in reevaluating Congress' solution to a specific legal and moral issue—the extent to which NICU physicians and nurses should aggressively intervene to preserve the life of critically ill newborns. Specifically, this Note will show how current law overlooks the problem of overtreatment of critically ill newborns and also creates a tendency to neglect several key factors in the caregiving process using illustrations from *Mixed Blessings*.

II. Major Themes of *Mixed Blessings*

A. *The NICU Professionals*

1. *The physicians*

Three types of physicians—senior physicians, fellows, and residents—make up the first level of the complex hierarchy of NICU personnel at Northeast Pediatric. Senior physicians act with almost unlimited authority and discretion to oversee the other professionals in the NICU and to set the course of treatment for newborn patients.[3] The senior neonatologist's responsibilities, partially self-imposed, do not end with providing medical services to newborns in the NICU; the successful senior physician also has responsibilities which require "a combination of clinical and organizational skills."[4] Another characteristic distinguishes neonatologists from most other practicing physicians—they are able to make the daily caregiving function of the NICU double as an ongoing laboratory for clinical research.[5] The most remarkable result of such a research orientation is the ability to routinely preserve the lives of neonates who, in the past, were no more than second trimester miscarriages.[6] One physician summed up the multi-faceted responsibilities of a ne-

3. *See id.* at 23.
4. *Id.* at 24.
5. *See id.* at 27-28.
6. *Id.* at 118-19.

onatologist: "This is the kind of place in which people assume you can be a brilliant administrator in the morning, a brilliant clinician in the afternoon, and a brilliant laboratory researcher in the evening."[7]

Because "[t]he demands for professional help are so heavy in newborn intensive care," senior physicians rely heavily on the help that resident physicians provide during their rotations in the NICU.[8] Residents immediately are faced with the barrage of medical and nonmedical problems that occur every day in an NICU. The neonatology fellows, who assist senior physicians in managing the NICU, are primarily responsible to train the residents.[9] However, teaching is often limited to "narrowly defined clinical skills to meet emergency needs."[10] The most significant learning comes from the incredible volume of cases residents face in the "trial by fire" atmosphere of the NICU.[11]

The combination of inexperienced physicians and the variety of medical factors affecting the health of a newborn makes the occurrence of mistakes inevitable.[12] The authors note that "[b]ecause patients are at high risk, the distinction between skill evaluation and patient evaluation often blurs in emergency medicine. . . . [W]as the therapy wrong or the case hopeless?"[13] Generally, mistakes in judgment or technical competence are excusable and quickly forgiven by other staff members, "provided the error was admitted and the one who made the mistake indicated a learn-from-experience attitude."[14] However, this is not the case when a physician's error is "normative"—"conduct [which] violates the working understandings on which action rests."[15] In other words, the senior physicians and staff are much less forgiving when an error is committed due to a failure to gather a consensus from other team members, a failure to request help from a more experienced physician, or the neglect of

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7. *Id.* at 24.

8. *Id.* at 28. Because the need for physicians is so great in NICUs as compared to other medical subspecialties, some residents "spend as much as one-half of their clinical hours working in newborn intensive care." *Id.* at 29.

9. *Id.* at 32-33.

10. *Id.* at 29.

11. *Id.* at 31 (quoting Frader, *Difficulties in Providing Intensive Care*, 64 PEDIATRICS 10, 13 (1979)).

12. *See id.* at 31, 37.

13. *Id.* at 37-38.

14. *Id.* at 40.

15. *Id.* at 39 (quoting C. BOSK, FORGIVE AND REMEMBER: MANAGING MEDICAL FAILURE 51 (1979)).

the NICU's accepted treatment policies.[16] Although preventing mistakes altogether is impossible, mistakes are drastically minimized by extensive monitoring of patients and frequent clinical peer review.[17]

2. The nurses

NICU nurses carry out diverse professional responsibilities and also occupy a rather flexible role in the NICU hierarchy. While nurses clearly find themselves beneath physicians on any NICU organization chart, the physicians—especially residents—often rely on nurses to go "beyond their own limited technical responsibilities."[18] One resident hesitantly acknowledged his dependence on a nurse's competence.

> During the morning rounds the resident made a special point of telling the attending physician how helpful it was to have had a nurse put the intravenous line in the baby. One baby needed something, another baby needed something else, and it was helpful that the nurse had taken care of the intravenous line in this case. He then laughed and said something to the effect, "Don't tell her I said so."[19]

In addition to their medical responsibilities to the newborns, nurses assume administrative responsibilities to monitor available bed space and the flow of patients. They also bear social responsibilities of interacting with families and even serving as a newborn's surrogate parent when necessary.[20] "Nurses also do dirty work."[21] When a patient's death is inevitable, the physicians usually leave nurses to interact with the parents, clear away equipment, and prepare the infant for transport to those who handle the corpses.[22]

Although nurses at Northeast Pediatric find themselves below physicians in the hospital hierarchy, they seek to organize and carry out their work as professionals.[23] Their primary efforts

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16. *See id.* at 39.
17. *Id.* at 37.
18. *Id.*
19. *Id.*
20. *Id.* at 58-59.
21. *Id.* at 60.
22. *Id.*
23. The authors address the nurses' struggles and successes concerning achievement of "professional status." *Id.* at 61-66. The primary obstacles to being perceived as professionals include the nurses' limited influence on important policies and treatment decisions and lack of respect from new physicians and physicians from outside the unit. *Id.*

involve an innovative model of organization referred to as "participatory management."[24] Participatory management centers around three key principles which are typically found in the workings of self-managed "professions." The first principle is "primary nursing"—one nurse, the "primary" nurse, takes "first-order responsibility for a patient."[25] The primary nurse's twenty-four hour responsibility for the infant increases the continuity of care over several nursing shifts, improves the quality of communication with the infant's family, and gives the nurse a personal stake in the infant's health.[26] Referring to the increased incentive provided by primary nursing, the nursing coordinator at Northeast Pediatric said, "When the primary nurse's name is on the isolette, her craving for knowledge goes up—the applications for library cards go up."[27]

The second principle of the nursing program is peer review. The nurses at Northeast Pediatric police themselves by evaluating one another. In addition to physician evaluations, they give both formal and informal feedback and impose their own sanctions such as changes in work hours or reductions in responsibility.[28] Finally, the third principle of participatory management is staff development. The nurses at Northeast Pediatric believe that as they educate themselves, they will naturally become increasingly involved in the more technical decisions made in the unit.[29]

3. *The social and psychological professionals*

The authors strongly emphasize the relatively minor role played by the NICU's non-medical personnel, such as social workers and psychologists. This emphasis makes it clear that the authors' bias was toward an increased and more integral involvement of these professionals. At Northeast Pediatric, the social service professionals participate in the resolution of a wide variety of issues, including implications of medical problems, par-

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However, the nurses have reached a respectable status *within* the unit itself due to their experience and reliability. *Id.* at 61-62.

24. *Id.* at 49.

25. *Id.* at 53 (citation omitted). Primary care—also referred to as "case ownership"—is a principle that applies to physicians as well, and the authors stress it as a theme throughout the book. *See id.* at 35-37.

26. *Id.* at 53-54.

27. *Id.* at 54.

28. *Id.* at 50-51.

29. *Id.* at 54-55.

ent-infant relationships, parents' social and psychological problems, relationships between the staff and parents, and psychological problems suffered by the staff itself.[30] However, the social workers and psychologists, themselves, do not choose their own cases; instead, they usually are only involved in complicated cases selectively referred by the nurses—such as those cases involving long stays in the unit or incompetent parents.[31] In fact, in some cases observed by the authors, the nurses actually attempted to protect an infant's family from social services personnel.[32]

According to the authors, several factors contribute to the exclusion of social workers and psychologists from the NICU's most routine and important work. First, these professionals are often viewed as "outsiders" by the medical staff who, for the most part, have worked together more closely and for a longer period of time.[33] Second, because the physicians' primary focus is limited to the medical necessities of infant patients,[34] physicians and nurses often neglect or forget to consult social service personnel even in cases where they are obviously needed.[35] Finally, the physicians often avoid consultation with social workers "because they [are] perceived as blurring the boundaries between medical and social issues."[36] As discussed in section III of this Note, physicians tend to consider only medical factors, disregarding other important factors such as economic and psychological problems.[37] And because physicians are the leaders of the NICU, they "set the tone regarding how important, or not, social service is to the unit."[38]

B. The Patient: Decision-Making and Caregiving

The caregiving role of the NICU staff at Northeast Pediatric extends well beyond the walls of the Level III nursery. In addition to the complex medical decisions made within the unit itself,[39] the staff must concern itself with what happens before

30. *Id.* at 76.
31. *Id.* at 73-74.
32. *Id.* at 73.
33. *Id.* at 70.
34. *See infra* notes 184-99 and accompanying text.
35. J. GUILLEMIN & L. HOLMSTROM, *supra* note 1, at 70-71.
36. *Id.* at 71.
37. *Id.*; *see also infra* notes 190, 195-98 and accompanying text.
38. J. GUILLEMIN & L. HOLMSTROM, *supra* note 1, at 72.
39. For a discussion of the NICU decision-making process, see *infra* section III.

the critically ill newborn arrives at the unit and with the care that the newborn will receive upon leaving the unit.

The primary considerations faced before newborns arrive at the NICU are the process of referrals from lower level nurseries, the safe transport of the infants once the unit receives a referral, and the problems created by incorrect treatment prior to transfer to the NICU. Because Northeast Pediatric—like most Level III NICUs—is a regional center, most of its cases are referred from a large general hospital, a large maternity hospital, and numerous small community hospitals.[40] Referrals to a regional Level III nursery like Northeast Pediatric usually come from local practitioners.[41] Unlike many medical specialties which are "client dependent," "[n]eonatologists are colleague dependent."[42] In fact, the roles of neonatologists and obstetricians are interdependent. The obstetricians rely on neonatologists to take care of the critically ill newborns referred to the NICU and also to communicate state-of-the-art "standards of newborn viability and the proper techniques for pretransport care."[43] In turn, neonatologists rely on obstetricians (and general practitioners) for referrals to fill the bed space in the NICU.[44] The primary problems with referrals are caused when obstetricians refer infants either who are completely beyond hope of saving or who are not sick and are referred to the NICU to comfort either the parents or the individual obstetrician.[45]

Another interesting component of the work at Northeast Pediatric is the transport of ill newborns from the referring hospital to the Level III NICU, usually performed by a team of one NICU nurse and one NICU physician.[46] The transport process creates both psychological problems for the parents and practical problems for the NICU staff. The transport necessarily separates the mother from her child and forces the father and other family members to decide whether they will stay with the mother or go with the infant.[47] The transport team is faced with

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40. *Id.* at 89-91.
41. *Id.* at 91.
42. *Id.* at 93.
43. *Id.* at 94. The authors point out that "[t]he recent Infant Doe regulation requiring maximum care for handicapped newborns has accentuated these pressures" which cause the obstetrician to rely heavily on her neonatology colleagues. *Id.*
44. *Id.* at 93-94.
45. *Id.* at 95-96.
46. *Id.* at 98.
47. *Id.* at 100-01.

the prospect of stabilizing the newborn for transport, explaining to the family where the baby will be taken, and dealing with the referring physician.[48] These difficulties are compounded by the fact that the transport team is "working on someone else's turf," often with less than adequate equipment.[49] After removing the infant from the referring hospital, the transport team then faces the difficulty of working in a moving vehicle.[50]

Once a newborn is admitted to the NICU, the unit's primary emphasis is on making a quick diagnosis and then determining the proper type and level of treatment.[51] In addition to the strictly medical processes, there is also a very human side to the treatment of newborn infants at Northeast Pediatric. The NICU staff puts great emphasis on "personifying" each newborn—both in the staff's own eyes and especially in the eyes of the newborn's parents.[52] The staff wants the newborns to have "names and possessions that give the infant a unique personality."[53] In fact, "[the nurses] encouraged parents to name even the smallest and most ill newborn and to bring in toys and clothes."[54] In addition, and probably as a result of the primary nursing program mentioned above,[55] the nurses attempt to "humanize" the newborns in reports to the parents by "talk[ing] positively about the infant's motivation, coping, and personality."[56]

By nature, a NICU is a temporary facility; when infants are "no longer in need of maximum treatment," the staff attempts to "free up beds for new and sicker patients."[57] The following short conversation makes light of the NICU's temporary nature:

> *Nurse*: "The baby's real cute, really cute."
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> *Fellow*: "As soon as they get too cute around here, it's out the door."[58]

In addition to the newborn infant's medical condition

48. *Id.* at 98-100.
49. *Id.* at 98.
50. *Id.* at 101-02.
51. *Id.* at 122-23. This decision-making process is discussed in detail in section III.
52. *Id.* at 135-37.
53. *Id.* at 136.
54. *Id.* at 136-37.
55. *See supra* notes 24-26 and accompanying text.
56. J. GUILLEMIN & L. HOLMSTROM, *supra* note 1, at 137.
57. *Id.* at 143.
58. *Id.* at 155.

(clearly the most important factor), the NICU staff considers several other factors when determining whether to discharge an infant. These factors include the "availability of other caregivers" and their ability to give adequate care, "the pressure to free up bed space in the Level III nursery," and whether the infant's needs require any specialized treatment available only at the Level III nursery.[59] Because physicians often worry about the quality of care infants might receive at other institutions,[60] physicians tend to err on the side of "keeping the baby too long rather than discharging one too soon."[61] To assist the other institutions, the NICU nurses carefully prepare "discharge plans" for the newborn's future care.[62]

Unfortunately, a newborn's death is often the cause for freeing up beds in the NICU. At Northeast Pediatric, the mortality rate usually ranges between fifteen and eighteen percent.[63] The authors point out how different types of deaths have varying effects on the staff and how the staff attempts to cope with these frequent tragedies. If a newborn is destined to die, the staff responds best to a sudden death, usually resulting from a failed resuscitation.[64] "This work lets the staff do what they do best because a resuscitation, successful or unsuccessful, is the epitome of intensive care."[65] The prolonged or "roller-coaster" deaths seem to have a worse impact on the staff's morale, primarily because they represent "a visible reminder to the staff that they have failed."[66] The authors also note that to cope with death the staff uses euphemisms, such as the baby is "checking out."[67] In addition, the staff sometimes chide each other with "gallows humor" or, alternatively, attempt to focus only on the technical aspects of caring for the dying infant.[68]

C. The Family

Although various national and world medical and health organizations have taken the official position that parents should

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59. *Id.* at 156-57.
60. *Id.* at 143-44.
61. *Id.* at 157.
62. *Id.* at 159.
63. *Id.* at 144.
64. *Id.* at 147.
65. *Id.*
66. *Id.* at 147-49.
67. *Id.* at 145.
68. *Id.* at 150-53.

make the decision about their child's treatment with help from physicians, the authors note that "American parents have little control over their newborn's referral or treatment."[69] However, the parents do play a very important role and are often the focus of the staff's attention and concerns. Because NICU physicians cannot have the type of relationship with newborns that they normally have with other patients, the physicians often look to the parents to fulfill the "patient half" of the physician-patient relationship. As other doctors rely on their patients "for feedback about the efficacy of treatment," NICU physicians rely on parents for feedback about their infant's progress.[70]

"During the time an infant is a patient in the NICU, the staff has definite expectations of the parents and strategies for managing them."[71] However, the rapid turnover of infants in the NICU makes it difficult for the staff to get to know parents well and even more difficult to follow up with problems the family may have.[72] The NICU nurses carry the primary burden of caring for parents and their needs.[73] The nursing staff generally has a "mistrustful" attitude about parents, especially those who visit the unit infrequently or who affect parents of other infants by being overly disruptive or emotional.[74] A primary goal of the nurses is to help parents to begin and continue the "bonding" process that has been interrupted by intensive care.[75] The NICU staff continually attempts to evaluate each newborn's family in terms of economic and psychological stability, as well as the parents' general willingness and ability to care for the child.[76] If the staff forms an extremely negative opinion of the parents and their apparent home life, the staff often prolongs the stay at the unit and in some cases even may alter the decision of how aggressively the infant will be treated.[77]

Communication to parents about their child's medical condition is also a high priority for the staff at Northeast Pediatric.[78] Frankness and consistency of reports to parents are the

69. *Id.* at 169.
70. *Id.* at 172.
71. *Id.* at 171.
72. *Id.* at 170.
73. *Id.* at 175.
74. *Id.* at 174, 176-78.
75. *Id.* at 179-80.
76. *Id.* at 182-86.
77. *Id.* at 185-86.
78. *Id.* at 186.

staff's most important communication goals.[79] However, the authors point out that there are many obstacles to communication in the NICU which tend to keep parents removed from most of the decision-making process. Physicians paternalistically withhold information because they believe the infant's treatment is their prerogative.[80] Also, physicians' language is sometimes too technical for the parents to understand clearly.[81] Finally, many of the NICU's goals—including expansion of the clinical frontier, research, and the training of residents—run counter to the parent's goals of finding out all they can about their infant and participating in the medical decisions.[82] The authors disapprove of these sometimes intentional obstacles to communication:

> [T]here is no particular guarantee that the interests of newborns are better protected when parents are prevented from playing a more active role. To the contrary, the staff's diminished sense of accountability to other responsible adults fosters a narrow focus on the infant's survival and can give greater latitude to latent experimentation and even neglect.[83]

D. Comparison of National and International NICUs

After explaining the everyday ongoings of the NICU at Northeast Pediatric in great detail and in very human terms, the authors—somewhat oddly—launch into a very general explanation of other NICUs they visited in the United States and in several foreign countries. The focus of the book quickly turns from personal relationships among the NICU participants and their decisions about individual infants to a categorical and statistical discussion of the entire field of neonatal care. Unfortunately, the latter discussion is somewhat superficial, and the authors are unable to maintain the same emotive level of persuasiveness that was possible with the examples and dialogue approach used to describe a single unit. While this abrupt switch from specific to general affects the overall congruency of *Mixed Blessings*, the national and international comparisons do serve one important purpose: they confirm that many of the chal-

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79. *Id.*
80. *Id.* at 187-88.
81. *Id.* at 188-89.
82. *See id.* at 189-94.
83. *Id.* at 197.

lenges faced at Northeast Pediatric are common to many other hospitals involved with neonatal intensive care.

The authors point out that not all NICUs are structured the same as Northeast Pediatric.[84] Some are much less regionalized, serving primarily a single general hospital.[85] Different circumstances are found in different types of hospitals such as general teaching hospitals, pediatric teaching hospitals, and non-teaching maternity and pediatric hospitals.[86] Another obvious contrast is between "inner-city public hospital[s]" and "elite private hospital[s]."[87] These differences in how hospitals are structured and where they are located have drastic effects on funding, on the hierarchal organization of individual NICUs, and on how and from where each unit receives its patients.[88]

Two organizational trends are common in United States' NICUs. First, due to the increasing expertise and efficiency required in a NICU, most Level III units are moving toward regionalization. In other words, a single Level III nursery may service several general care hospitals.[89] The regionalization trend has led to a second trend—economic competition among NICUs.[90] Components of the increasing competition include more intricate personal referral systems, formal referral contracts among hospitals, and emphasis on the efficient management of each unit.[91]

Another interesting dichotomy is emerging as the neonatology field expands and becomes more competitive. Some units, including Northeast Pediatric, have begun to cater to a more wealthy patient population by "solidifying contract relations with suburban hospitals."[92] As a result, other hospitals with more poverty-stricken patients often are forced to rely on Medicaid payments.[93] The dichotomy between poor and rich patient populations has accentuated the already known fact that there is a strong association between poverty and premature

84. *Id.* at 229.
85. *Id.*
86. *Id.* at 231.
87. *Id.*
88. *See generally id.* at 232-40.
89. *Id.* at 229, 245.
90. *See id.* at 236, 239.
91. *See id.* at 236-39.
92. *Id.* at 244.
93. *Id.*

births;[94] a problem that the authors also discuss in the international context.

In their international comparison, the authors emphasize the prominent differences between neonatal intensive care in the United States and in three foreign countries—England, the Netherlands, and Brazil. In England, constraints imposed on NICU physicians by government policymakers are greater in two respects than in the United States. First, there is a rather strict, "government-imposed budgetary limit on health care expenditures."[95] Although physicians in England do not allow economic factors to dominate individual treatment decisions, they admit that the problem of scarce resources is constantly considered on an overall basis.[96] Second, the "multiple tiers of government policy-making bodies" in England control and limit use of the most progressive experimental technologies in neonatal intensive care.[97] Another interesting difference—surprisingly driven by public sentiment rather than government control—is the physicians' practice of actively involving parents in treatment decisions.[98]

In the Netherlands, the principal difference in neonatal care lies in a key statistic—an 8.1 per 1000 infant mortality rate, as opposed to the United States rate of 11.1 per 1000.[99] Oddly, this low mortality rates exists despite (although many midwives claim because of) the significant proportion of home births that still occur in the Netherlands.[100] The authors submit that there are two related reasons for the extremely low mortality rate. First, "[p]overty, which is strongly associated with prematurity and infant death, has been virtually eliminated" in the Netherlands.[101] Second, "prenatal care is [both] available and taken advantage of" much more often in the Netherlands than in United States.[102]

Brazil's significantly higher infant mortality rate (82.4 per

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94. *Id.*
95. *Id.* at 249.
96. *Id.* at 251.
97. *Id.* at 249.
98. *Id.* at 254-55.
99. *Id.* at 230, 256 (according to a 1982 study).
100. *Id.* at 256.
101. *Id.*
102. *Id.* at 257 (explaining how most Dutch citizens belong to government-sponsored medical plans).

1000)[103] is explained by "[b]oth economic marginality and the precarious nutritional status of substantial sectors of the urban population . . . ."[104] This economic disparity dictates that only the most wealthy—usually those who can afford insurance—have access to neonatal technology comparable to that of the United States.[105] Because the problems Brazil experiences are primarily economic in nature, the authors conclude that "public health and prevention would probably be a more cost-effective, practical solution to the problem of infant mortality than technology transferred from industrialized countries."[106]

E. Policy Recommendations

The authors' recommendations may appear to be based on a complete study of United States NICUs, but, in fact, only the observations at Northeast Pediatric are sufficiently complete to make such overarching recommendations. Consequently, the authors should explicitly recognize the limited basis on which they draw their conclusions. However, based on their objective and very complete observations at Northeast Pediatric, many of their recommendations appear to be sound.

The authors claim that the primary problems with neonatal care in the United States exist because recent expansion "has taken place in the absence of a comprehensive national plan for maternal and infant health."[107] Consequently, the authors recommend an integrated reform effort on the part of three groups—the individual NICU, the hospital administration, and the government.[108]

At the NICU level, the authors suggest that aggressive intervention is caused partially because the staff has no established evaluation method, but allows a "perception of crises [to] determine . . . ultimate decisions."[109] To alleviate this problem, the authors recommend that, after an initial stage of aggressive resuscitation, the staff be required to perform a standard reeval-

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103. *Id.* at 230 (according to a 1979 study).

104. *Id.* at 263.

105. *Id.* The income level of a Brazilian infant's parents likewise determines the quality of hospital available, access to cesarean deliveries, and availability of transport services. *Id.* at 264.

106. *Id.* at 268.

107. *Id.* at 271.

108. *Id.* at 272.

109. *Id.* at 273.

uation of the infant's condition.[110] Also, to protect extremely premature babies from abusive overtreatment, the authors suggest that physicians be required to label infants with certain serious conditions—such as extremely low birth weight—as "experimental."[111] This would allow parents (and society) to be informed of the nature of treatment and would encourage the staff to follow carefully prescribed protocol.[112]

The authors also recommend the creation and increased involvement of hospital review committees to protect the welfare of NICU patients. Such committees would "serve . . . as a means for physicians, nurses, social workers, and other hospital employees to clarify ethical issues, gain legal protection, shape hospital policies, and air professional disagreements."[113] In addition, the authors outline several ways that these committees could resolve current NICU problems such as discontinuous care by rotating residents, poor treatment by transferring hospitals, and the lack of adequate clinical follow-up and feedback after infants leave a unit.[114]

At the government level, the authors suggest that the Baby Doe rules—which address only infant neglect—be altered to prevent the dangers of overtreatment as well.[115] Also, the authors recommend that the United States follow the lead of countries such as the Netherlands by more carefully "allocat[ing] [financial] support among different levels of medical care."[116] Specifically, the government should allocate more support to preventative health care measures, such as prenatal counseling.[117] Finally, the authors suggest that if government policy requires aggressive intervention in almost all cases, "then society also incurs the obligation that these children receive the necessary services to make their lives as rewarding as they can be."[118]

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110. *Id.*

111. *Id.* at 274.

112. *Id.*

113. *Id.* at 277. For a detailed discussion of such committees, see Shapiro & Barthel, *Infant Care Review Committees: An Effective Approach to the Baby Doe Dilemma?*, 37 HASTINGS L.J. 827 (1986).

114. J. GUILLEMIN & L. HOLMSTROM, *supra* note 1, at 278-79.

115. *Id.* at 281. The Baby Doe rules are discussed at greater length in the next section of this Note. *See infra* notes 119-37 and accompanying text.

116. J. GUILLEMIN & L. HOLMSTROM, *supra* note 1, at 282.

117. *Id.* at 282-83.

118. *Id.* at 283-84.

III. Aggressive Intervention and the Baby Doe Regulations—How Far is Too Far?

A. The Baby Doe Regulations

Mixed Blessings was written in the wake of the Baby Doe legislation. When Congress passed the legislation, it had certain ideas—although not very specific—about who should make the intervention decision and what factors should be a part of the treatment decision. While others have exhaustively analyzed and evaluated Congress' response to this complicated legal and moral issue,[119] the purpose of this section of the Note is to review some of the objective observations made by the authors in *Mixed Blessings* which may shed light on how and whether Congress' legislation has affected day-to-day decision-making in the NICU. This section will discuss the authors' findings about whether aggressive intervention is indeed the norm in an NICU, who decides whether to withdraw treatment from a newborn, and what factors are considered in that decision. In addition, and perhaps more importantly, the book's observations may make policy makers—including Congress—aware of some unforeseen consequences of the legislation's implementation and of some unknown ingredients which are factors in the decision-making process.

The primary impetus for federal legislation regarding the nontreatment of critically ill newborns was the case of "Baby Doe," who was born in Bloomington, Indiana, in 1982.[120] Baby Doe suffered from Down Syndrome as well as from a blocked digestive track which could have been corrected with surgery.[121] Despite challenges from the hospital,[122] the parents refused to consent to the corrective surgery and requested that food and water be withheld.[123] After several days, and before the hospital could acquire court relief, Baby Doe died.[124]

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119. *See, e.g., supra* notes 129-37.

120. Jackson, *Severely Disable Newborns: To Live or Let Die?*, 8 J. Legal Med. 135, 143, 145 (1987).

121. *Id.*

122. The hospital sought injunctive relief from the Superior Court of Monroe County, Indiana, on the grounds that the parents had no right to withhold treatment. The court ruled that the parents had "the right to choose a medically recommended course of treatment for their child in the present circumstances." *In re* Treatment and Care of Infant Doe, No. GU8204-004A (Monroe County Super. Ct., Apr. 12, 1982), *cert. denied, reprinted in* 2 Issues in L. & Med. 77-80 (1986).

123. Jackson, *supra* note 120, at 143.

124. *Id.* at 144.

After failed attempts by federal agencies to restrict nontreatment decisions based on statutes in force at the time,[125] Congress responded to the Baby Doe dilemma by enacting the Child Abuse Amendments of 1984.[126] The amendments made the failure to treat a handicapped infant a violation of the Child Abuse Treatment and Prevention Act.[127] The amendments, in their key provision, defined "withholding of medically indicated treatment" as

> the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's or physicians' reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's or physicians' reasonable medical judgment—
>
> (A) the infant is chronically and irreversibly comatose;
>
> (B) the provision of such treatment would—
>
> (i) merely prolong dying;
>
> (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions; or
>
> (iii) otherwise be futile in terms of the survival of the infant; or
>
> (C) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.[128]

Instead of making the nontreatment provisions absolutely mandatory, the statute makes state implementation of the requirements a condition to receiving certain grants for state child abuse programs.[129]

Although Congress did not provide sufficiently specific

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125. For a complete account of the Department of Health and Human Services' attempts and failures to promulgate corrective rules under section 504 of the Rehabilitation Act of 1973, see Mims, *The Plight of the Handicapped Infant: The Federal Response*, 15 U. BALT. L. REV. 449, 452-69 (1986). *See also* Jackson, *supra* note 120, at 145-53.

126. Child Abuse Amendments of 1984, Pub. L. No. 98-457, § 121, 98 Stat. 1749, 1752 (1984) (codified as amended in scattered parts of The Child Abuse Prevention and Treatment Act of 1974, 42 U.S.C. §§ 5101-5107 (1988)).

127. *Id.*

128. *Id.* § 121(3) (current version at 42 U.S.C. § 5106g(10) (1988)).

129. 42 U.S.C. § 5106a(a), (b)(10) (1988).

guidelines to allow a physician to make an intervention decision in a particular newborn's case,[130] the wording of the Child Abuse Amendments does make Congress' intent clear in at least a few areas. First, Congress intended that the states ultimately determine whether such aggressive treatment standards should be implemented. Otherwise, Congress would not have made implementation of the requirements merely a condition to receive federal grants. Second, Congress clearly intended that the physician—apparently without the input of parents, social workers, or administrators—make decisions regarding intervention. The key provision's structure actually requires the physician to make two decisions based on "reasonable medical judgment": first, which method of treatment "will be most likely to be effective in ameliorating or correcting all [life-threatening] conditions" suffered by the infant; and second, whether the infant's condition meets any of the statute's exceptions which would justify nontreatment.[131] Finally, the exceptions to the general rule of aggressive intervention are indicative of what factors Congress intended physicians to consider when deciding whether to treat a newborn patient. The factors or conditions justifying nontreatment which a physician may consider are inflexible and relatively few in number. In determining whether to withdraw treatment, physicians may consider only the prospects of imminent death, whether the patient suffers from chronic and irreversible comatose, and whether treatment appears to be both futile *and* inhumane.[132]

Although almost every state has implemented the Baby Doe requirements, a host of critics has called for reevaluation of the rules for several reasons, all related to the one-dimensional focus of the Baby Doe legislation—to prevent child neglect. A common argument is that because "parents are most intimately and permanently affected by the treatment decision whether it results in the life or death of [the] child," they—along with the physician—should be involved in the treatment decision.[133] An-

130. The Joint Explanatory Statement by Principal Sponsors of Compromise Amendment Regarding Services and Treatment for Disabled Infants stated that "no provision of [the Child Abuse Amendments] may be construed to authorize . . . establish[ment of] standards prescribing specific medical treatments for specific conditions. . . ." 130 CONG. REC. S9319, S9320 (daily ed. July 26, 1984), *reprinted in* 1984 U.S. CODE CONG. & ADMIN. NEWS 2969, 2972.

131. *See* 42 U.S.C. § 5106g(10) (1988).

132. *Id.*

133. Jackson, *supra* note 120, at 136-37; *see also* Note, *Treatment Decision-making*

other criticism is aptly summarized by one author: "As much—or possibly even greater—harm is done by preserving an infant in order for it to mature into an unwanted life than by killing a baby which, if left to die, might have been perfectly fulfilled."[134] The Baby Doe rules have also been criticized for failing to address the enormous costs associated with a strict policy requiring intervention in almost all cases.[135] Critics have encouraged policy makers to consider allocating some of these resources to more beneficial areas such as preventative prenatal care programs.[136] The authors of *Mixed Blessings* lodge another complaint against the Baby Doe legislation that is particularly ironic considering that the legislation's purpose is to protect newborns' rights. They argue that, given the status of present law and the tendency for experimentation in the neonatology field, infants are as vulnerable to *overtreatment* as they are to neglect.[137]

B. The Presumption—Aggressive Intervention

Mixed Blessings makes one thing overwhelmingly clear: the norm—at least at Northeast Pediatric—is maximum intervention to aggressively treat critically ill newborns.[138] The authors observed that "[i]n the overwhelming majority of cases, the most fundamental decision—whether or not to 'go all out'—was easily and routinely made, and the answer was in the affirmative."[139] Usually, the only decision is about what "course of treatment to take, not whether to treat."[140] Even when a newborn suffers from "severe neurological damage," the unit makes "vigorous attempts" to save the newborn.[141]

There are many reasons why the staff at Northeast Pediatric makes aggressive treatment the rule instead of the exception. Interestingly, the authors did not mention the Baby Doe legisla-

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in the Neonatal Intensive Care Unit—Governmental Regulation Compromises Parental Autonomy, 13 WM. MITCHELL L. REV. 951, 983 (1987).

134. Wells, *Whose Baby Is It?*, 15 J. L. & SOC'Y 323, 338 (1988).

135. *See* Note, *supra* note 133, at 954.

136. *Id.; see also* J. GUILLEMIN & L. HOLMSTROM, *supra* note 1, at 282-83.

137. *See* J. GUILLEMIN & L. HOLMSTROM, *supra* note 1, at 272, 281.

138. *See id.*, at 123 (this was true from the "moment of referral through transport [out of the n.i.c.u.]").

139. *Id.* at 114.

140. *Id.* at 115.

141. *Id.* at 124.

tion as a major factor in the decision to intervene.[142] The primary impetus for aggressive treatment is the extreme uncertainty surrounding each infant's medical condition. Scheff's influential article, quoted by the authors, aptly explains how the medical profession in general deals with uncertainty: "Judging a sick person well is more to be avoided than judging a well person sick . . . . The rule in medicine may be stated as: 'When in doubt, continue to suspect illness.' . . . It is far more culpable to dismiss a sick patient than to retain a well one."[143]

A resident's comment about a particular infant confirmed that this is the philosophy at Northeast Pediatric: "Sure, he looks funny, but you don't know if he'll be a good baby. If you can't prove zero prognosis, you're stuck with treating."[144] The authors note that one problem with a policy of automatic aggressive treatment is that physicians tend "to judge certain newborns as more viable (more healthy) than they really are."[145] On the other hand, such a policy's primary benefit is avoidance of "the possibility that the individual who might benefit from treatment will not be treated."[146]

One factor contributing to uncertainty in an NICU is the time required to collect sufficient information to make a treatment decision about each newborn. At Northeast Pediatric, "[t]he basic rule was that until one has information that gives one a reason not to treat, one is obligated to treat."[147] Due to limited information at early stages of treatment, the NICU physicians make incremental decisions based on what little information is available.[148] This type of "incrementalism" causes one small treatment to lead to another; the cumulative result is aggressive treatment—sometimes overly aggressive—despite the lack of a conscious decision to do so.[149] Likewise, once the staff takes some aggressive steps—often due to uncertainty—they are

142. *See infra* note 196 and accompanying text.

143. J. GUILLEMIN & L. HOLMSTROM, *supra* note 1, at 125 (quoting Scheff, *Decision Rules, Types of Error, and Their Consequences in Medical Diagnosis*, 8 BEHAV. SCI. 97, 99 (1963)).

144. J. GUILLEMIN & L. HOLMSTROM, *supra* note 1, at 123.

145. *Id.* at 125.

146. *Id.* at 126 (quoting D. CRANE, THE SANCTITY OF SOCIAL LIFE: PHYSICIANS' TREATMENT OF CRITICALLY ILL PATIENTS 204 (1975)).

147. J. GUILLEMIN & L. HOLMSTROM, *supra* note 1, at 124.

148. *See id.* at 130.

149. *See id.* at 130-31.

hesitant to withdraw treatment because at that point they have made an "investment" in the patient.[150]

Another element of uncertainty is caused by the difficulty of evaluating the effectiveness of the newest and most innovative forms of neonatal treatment. As the authors note, because neonatologists work with a "new patient population" of increasingly younger and more critically ill newborns, they "must make decisions about some patients . . . who represent types of cases for which there have been few or no survivors."[151] In other words, the newness of some treatment methods necessarily precludes there being any infants who have grown old enough to serve as determinants of the methods' effectiveness.[152]

The authors point out that the uncertainty in neonatology, unlike other progressive medical fields, is not likely to decrease. "In expanding the unit's services to borderline and even experimental cases, neonatologists increase the degree of uncertainty they must face in their work."[153] Also, unlike scientists in many nonmedical fields, neonatologists do not base their decisions on statistical data to determine a particular infant's opportunity for survival.[154] Instead, they focus on the "experimental, case-by-case advancement of the birth weight frontier" and "on the exceptional case, the 'write-off' who survived against all the odds."[155] One fellow at Northeast Pediatric commented on why statistical uncertainty does not play a large role in making individual decisions. "We went over the records and one-third had looked so bad that there had been discussion about taking them off the ventilator. And now at age three, they're walking around normal. . . . That's why it's so hard to stop."[156]

In addition to the uncertainties involved, the fact that members of the NICU staff see themselves as "advocates" for each newborn patient also contributes to the decision to intervene.[157] Unlike other patients, physicians cannot rely on a newborn to give feedback or to react emotionally to treatment. The

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150. *Id.* at 131-32.

151. *Id.* at 126.

152. An attending physician at Northeast Pediatric estimated that a child must reach the age of eight before the effectiveness of the child's treatment may be definitively determined. *Id.* at 126.

153. *Id.* at 125.

154. *Id.* at 128.

155. *Id.*

156. *Id.* at 128-29.

157. *Id.* at 134.

newborn is a "social and physiological unknown"—the infant's total vulnerability and lack of a "visible personal past" make it different from other patients.[158] Because a critically ill newborn is unable to defend itself and has so many factors working against it, the staff takes a "partisan position" that the newborn "deserves every chance" to defy the negative factors.[159]

Another primary determinant of aggressive intervention is "the sense of mission of the senior physicians and the position of authority that allows them to carry out that mission via the unit team."[160] Their mission is to advance the clinical frontier of treating more premature and more critically ill newborns.[161] The following conversation is indicative of both the mission and its success to date:

> *Nurse*: "We're doing all right with twenty-four-weekers. But this baby was borderline—the eyes were still fused. You can't afford to play that game and say it's not viable. At twenty-four weeks you have to assume they may survive."
>
> *Consulting physician*: "When we were house officers back in the dark ages in 1974 there was no question—the twenty-four-weekers didn't survive. But it will get earlier and earlier."[162]

Also, because the sophistication of medical technology and equipment increases, physicians tend not to allow even the most seriously ill newborns to die from causes that are technically preventable—such as blocked tubes or lack of antibiotics.[163] According to the NICU physicians, "the child should 'die of his disease.' "[164] In short, "the rationale for heroic treatment rests on the belief that the hospital's technology optimizes the single most important goal of the service: physical survival."[165]

A final factor leading to intervention is the NICU staff's common practice of seeking a "team consensus" before withdrawing treatment.[166] This practice is so pervasive that even a single resident's or nurse's objection to nontreatment can "[tip]

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158. *Id.* at 111-12.
159. *Id.* at 134-35.
160. *Id.* at 118.
161. *Id.* at 118-19.
162. *Id.* at 119.
163. *See id.* at 133-34.
164. *Id.* at 133.
165. *Id.* at 122.
166. *Id.* at 121.

the balance toward aggressive treatment."[167] Parents also play a critical role in the team consensus concept. The staff "prefer[s] to have parental agreement before actually withholding treatment."[168] In short, one dissenting voice in effect vetoes a nontreatment decision strengthening the norm of aggressive intervention.

In summary, Congress' intention that physicians aggressively intervene is being fulfilled in almost all cases although not for the reasons Congress contemplated.

C. *Who Decides Whether to Intervene?*

Although others influence the decision, the senior physician ultimately determines what treatment will be administered to a newborn. Because physicians bear "the responsibility for saving the infant's life," the determination is most often to treat aggressively.[169] Despite the ultimate authority of senior physicians, "there exists a norm that the staff should collectively air case problems about withdrawing or limiting treatment."[170] It is most often young residents and nurses who question a physician's almost automatic decision to intervene.[171] However, senior physicians usually use their authority to "[pull] rank" on the residents and nurses and to stick to their initial decision to treat aggressively.[172] One nurse commented on her ideological disagreements with a particular senior physician: "When the baby was seizing and obviously had brain damage, there were some feelings of, 'Why are we supporting the baby?' About operating if the baby will die anyway. These were mostly nursing concerns, and medicine was very aggressive. You get so you don't fight them anymore."[173]

Although *Mixed Blessings* indicates that the senior physicians at Northeast Pediatric are the ultimate decision-makers, the issue still exists whether others—such as parents or ethics committees—should be involved in the process. The authors' ob-

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167. *Id.*

168. *Id.* This need for parental consensus is interesting in light of the Baby Doe statute's mandate that nontreatment decisions be made "in the treating physician's or physicians' reasonable medical judgment. . . ." 42 U.S.C. § 5106g(10) (1988).

169. J. GUILLEMIN & L. HOLMSTROM, *supra* note 1, at 121.

170. *Id.* at 119-20.

171. *Id.* at 119.

172. *Id.*

173. *Id.* at 120.

servations tend to show, though only implicitly, that involvement of others may be difficult. At least in the initial stages of treatment, the decision whether to intervene or to withhold treatment as well as the determination of potential consequences requires on-the-spot processing of highly complex information.[174] "When you walk in, you can see. You get a feel for which babies are viable. You put a lot of things together—color, activity, how the baby responds, lab values, responses to treatment."[175] Once the physician sets the initial course of treatment, it becomes more difficult to decide to withdraw treatment. Of course, the issue of parental involvement becomes more poignant during the later stages of treatment after physicians have definitively diagnosed the nature of a newborn's illnesses and can speculate with greater certainty as to the newborn's clinical outcome.

In summary, it appears that Congress' mandate that *physicians* make treatment decisions in their reasonable medical judgment is also being carried out much as Congress intended. However, it is inevitable that those who become emotionally involved—such as parents, nurses, and social workers—will have some influence on treatment decisions.

D. Factors that Influence the Intervention Decision

Several factors have emerged as most influential in determining whether the NICU staff should intervene and aggressively treat a newborn patient; on the other hand, there are other arguably important factors which are all but ignored. As mentioned above, "[a]lmost all of the factors governing the treatment of these infants work in the direction of the unit's giving maximum aggressive intervention rather than limiting, withdrawing, or withholding it."[176] However, only the unit's borderline cases—a small percentage of total cases—lead "to agonizing staff discussions about the appropriate aggressiveness of intervention."[177] In borderline cases, "[t]he newborn typically [is] either without brain activity, dying, or suffering from a known ter-

174. *See id.* at 114-16.

175. *Id.* at 115.

176. *Id.* at 118.

177. *Id.* at 116. Most of these cases involve infants that "were so ill that they either died soon (in 9 days or less) or they remained a very long time in intensive care (68 to 143 days)." *Id.*

minal condition."[178] Such cases often cause "the staff to reflect on the value of treatment" as opposed to the likelihood of success.[179] Staff members are uncomfortable with this role they refer to as "playing God."[180] The authors elaborate on what makes the borderline decisions so difficult. "NICU technology can prolong suffering and postpone an inevitable death in ways never before possible. It can also save permanently damaged children who, in earlier times, simply would have died."[181] In these "borderline" cases, several key factors influence the decision whether to withdraw treatment.

The primary factor the NICU staff considers in the intervention decision is the seriousness of the infant's medical condition. More specifically, "[t]he neurological status of the infant is the most important outcome characteristic by which clinicians judge normalcy."[182] The authors observed that

> [n]eurological damage does not inevitably result in less aggressive treatment. Indeed, physicians at Northeast Pediatric often persevered in spite of evidence such as extensive brain bleeds and serious, overwhelming neurological compromise. However, neurological damage in combination with multiple medical problems could justify the rare decision to withhold treatment.[183]

Severe chromosomal anomalies are also sufficient justification for withdrawing treatment. A physician explained that chromosome tests are run as early as possible because the "test might reveal a disease that would severely limit the infant's life span to, say, a few months, and this fact would justify limiting intervention."[184] This basic idea is summarized by a sign on one physician's wall in another hospital: "If God gives you an infant but takes away the lungs, heart, kidney, and brain, maybe He's trying to tell you something."[185]

Physicians also consider another factor that is somewhat disease-neutral—the infant's will to live.[186] In some cases, "an

178. *Id.*
179. *Id.* at 118.
180. *Id.*
181. *Id.*
182. *Id.* at 127.
183. *Id.*
184. *Id.* at 123.
185. *Id.* at 133.
186. *Id.* at 135-36.

infant's staying power [is] perceived as creating an obligation to initiate treatment—perhaps even against the staff's wishes."[187] In essence, the perceived will of the infant "shifts the physician's decision-making authority to the infant and implies that the infant is responsible for what happens."[188]

E. Factors Not Considered in the Intervention Decision

The above-mentioned factors are only some of the many tangible and intangible variables that NICU physicians consider when deciding whether to withdraw treatment. Such a listing of factors, however, raises a related issue: Do physicians fail to consider other relevant issues when they make treatment decisions? What about factors that Congress did not (or could not) codify in the Baby Doe legislation? The authors point out that physicians are taught to adopt a "reductionist mode of thinking" in treating their patients.[189]

> The emphasis on analytic thought . . . restrict[s] value questions about the overall consequences of medical intervention. As long as there was a treatable organ, intervention was seen as justified. This narrow focus on pathology obscured the broader view of the patient as a potentially full social being and celebrated instead partial clinical victories.[190]

The result is aggressive intervention and "the relative absence of humanistic concern[s]."[191]

The physicians' lack of humanistic orientation is especially evident in the authors' contrast of the behaviors of physicians and nurses. " 'Nurses are more holistic,' that is, they consider long-term social consequences in evaluating cases."[192] They often criticize physicians "for being overly aggressive, concentrating on clinical problems in isolation from clinical outcome."[193] "Nurses, more often than physicians, work with mixed feelings about patients; that is, they can actively work to save a child and simultaneously hope that the child will not survive."[194]

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187. *Id.* at 136.
188. *Id.*
189. *Id.* at 132.
190. *Id.* at 132-33.
191. *Id.* at 132.
192. *Id.* at 119.
193. *Id.* at 119-20.
194. *Id.* at 120.

There is a similar rift between the physicians and social workers. One social worker said,

> I was thinking of both mother and child. They [the physicians] were thinking of just the baby. The physicians' orientation is very much for the baby's life. When I mentioned the relationship of mother and child, [the unit director] said, "The ethicists tell us we can't consider this. Our responsibility is for the baby." He is absolutely committed to a neonatal unit that is keeping the babies alive.[195]

Physicians have been accused—especially after and because of the Baby Doe legislation—of excluding parents completely from the treatment decision. However, the authors claim that parents do affect the decision whether to withhold treatment, but only if the parents are in favor of aggressive treatment. "Parents who want more medical support are listened to, but parents who are adverse to saving a critically ill or disabled newborn at all costs have a strenuous time opposing the staff's opinion to the contrary."[196] "[P]arents' acceptance of brain damage positively influence[s] aggressive intervention" in borderline cases in which the staff considers withdrawing treatment.[197] With respect to removing a particularly ill newborn from the respirator, one NICU fellow commented, "[W]e couldn't do that unless the parents were in agreement. We wouldn't even think of doing it without that."[198] In short, physicians do consider the fact that parents desire aggressive treatment into their intervention decision. On the other hand, physicians downplay input from parents who favor *nontreatment*. "[A]lthough physicians are aware that a severely damaged child has a major impact on a family, their goal is to screen out such information, especially if it is information about parental rejection."[199]

Likewise, the NICU staff ignores other external factors related to the decision to intervene aggressively. For example, physicians never allow economic costs—either to the hospital or

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195. *Id.* at 135.

196. *Id.* at 141 (citation omitted). Physicians—with the help of other nonmedical professionals—can and do exert great pressure on parents to consent to withdrawal of treatment in cases in which survival is improbable and parents have "unrealistic attitudes." *Id.* at 121-22, 139.

197. *Id.* at 138. Parents may be strongly "committed to their infant's survival at all costs" when they have experienced difficulty with becoming pregnant in the past or know they will be unable to have future children. *Id.* at 137.

198. *Id.* at 121.

199. *Id.* at 134.

to the parents—to influence their treatment decisions.[200] In addition, physicians do not allow the law to have a significant influence on the level of treatment; at most, the law is a "remote backdrop" in treatment decisions.[201] This observation is especially ironic because it was made so soon after enactment of the high-profile Baby Doe legislation. Finally, the NICU physicians are not receptive to input even from bodies within the hospital community, such as "review boards or ethics committees."[202] In short, the NICU staff at Northeast Pediatric limits its decision-making factors to the unit's "own normative clinical criteria."[203]

Regardless of whether the Baby Doe legislation is the cause, it is clear that NICU physicians—at least at Northeast Pediatric—limit their decision-making criteria to factors affecting an infant's medical viability. This limitation seems to be in accord with Congress' intent as stated in the Baby Doe statute.[204]

IV. Conclusion

The authors' observations in *Mixed Blessings* serve as a valuable basis against which interested parties—including parents, physicians, nurses, hospital administrators, and local and federal governments—may compare Northeast Pediatric to other NICUs and also evaluate whether similar NICUs are functioning in accordance with proper societal values. The authors' discussion of interaction among the various NICU professionals is enlightening—especially the innovative ways in which the nurses at Northeast Pediatric are expanding their roles in an effort to reach the "professional" ranks. The authors also point out the less than obvious logistical complexities involved in soliciting referrals, transporting newborns, managing bed space, and discharging NICU infants to lower care facilities. Additionally, *Mixed Blessings* illustrates the sociological and economic reality that the process of referrals and discharges between primary care hospitals and regional NICUs has become a separate and growing industry within the larger world of hospital administration.

Mixed Blessings also sheds valuable light on the effect—and

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200. *Id.* at 141.
201. *Id.*
202. *Id.* at 142.
203. *Id.*
204. *See supra* notes 126-28 and accompanying text.

the wisdom—of the 1984 Baby Doe legislation. The legislation appropriately addressed infant neglect problems necessary to prevent occurrences similar to the infamous Baby Doe case. However, Congress may have been somewhat hasty and near-sighted in its enactment of the Child Abuse Amendments of 1984. Congress attempted to make comprehensive changes in the area of neonatal intensive care based solely upon a single problem. The authors' observations in *Mixed Blessings* suggest that Congress may have been excessively one-dimensional in its assessment of how to protect NICU newborns. In addition to protection from undertreatment, infants may need some protection from overtreatment by research-minded physicians and by the medical process in general.

Congress may want to consider several ways to protect infants from overtreatment. The authors recommend that newborns with specific types of serious illnesses be identified as especially at risk to overtreatment and experimentation. The authors, along with other critics, suggest that increased autonomy on the part of parents may serve to temper the apparent imbalance toward excessive treatment. As long as physicians have authority to prevent situations similar to Baby Doe's, increased parental participation should not thwart Congress' intent regarding infant neglect.

Finally, the authors suggest that Congress evaluate the costs associated with a policy of aggressive treatment in almost all cases. The authors, supported by other critics and by examples from foreign governments, suggest that some dollars may do more good for newborns if spent in preventative programs such as prenatal care. A final skeptical observation by the authors may moot all of these recommendations to Congress and other policymakers: NICU physicians seem not to respond in a significant way to statutory rules. Instead, their treatment decisions are driven by what they perceive as medical imperatives.

Reviewed by Monte M. Deere, Jr.