Baby Does and the Right to Lifesaving Treatment

While the 1970s saw a decline in efforts to prevent people with disabilities from having children, the 1980s saw an increase in efforts to deny them the right to live.

In the 1970s, they were a number of cases where children born with disabilities were denied lifesaving surgeries. In some cases, doctors left the decision totally up to the parents who refused the surgery because they were worried about the financial and emotional burden of raising the child. Many of these cases involved children with Down Syndrome (or Trisomy 21) with esophagheal and/or gastrointestinal blockages. If left untreated, this blockage would cause the child to starve to death. In other cases, doctors and families jointly decided not to treat the infant. (Mercurio, 2009)

The Courts Weigh In

Several court decisions set the stage for the landmark cases related to the right to lifesaving treatment that took place in the 1980s.

In *Schloendorff v. Society of New York Hospital,* the New York Court of Appeal ruled in 1914 that the right to self-determination was important. In the opinion of the court, Justice Benjamin Cardozo wrote:

> *Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages. This is true except in cases of emergency where the patient is unconscious and where it is necessary to operate before consent can be obtained.*

Unfortunately, this ruling applied specifically to adults, not to children with disabilities facing life-threatening situations. In this situation, parents and guardians are often believed to have the right to give consent for a child’s medical treatment.

Maine Medical Center v. Houle was the first legal challenge to parental decisions related to medical treatment for newborns with anomalies. In 1974, the Supreme Court of the state of Maine ruled that parents did not have the right to withhold lifesaving treatment and that doing so constituted neglect. The ruling included two other important points. First, a guardian cannot withhold consent for lifesaving medical measures. Second, the ruling affirmed that children with physical or mental impairments have the same right to life as other children. (Kindred, 1976, p. 78)

However, this ruling was limited to those situations in which someone was willing to advocate for the child’s right to live.

During the 1980s, a number of advocates emerged. One particularly visible and vocal advocate was C. Everett Koop, the Surgeon General of the United States from 1982 to

1989. Koop and others intervened in two critical cases that are often called the “Baby Doe” cases. These advocates urged Congress to develop and adopt the Baby Doe Amendment to the Child Abuse Law. The Amendment was passed in 1984.

Indiana Baby Doe

In 1982, a baby boy was born in Indiana with Down Syndrome and a tracheoesophageal fistula. The upper part of the newborn’s esophagus was not connected to the lower part. Surgery was both possible and likely to succeed. Without it, the baby would die.

The mother’s obstetrician had a particularly narrow view of Down Syndrome. He told the parents that their baby would not have any quality of life, even if the surgery were successful. Based on this advice, the baby’s parents “agreed not to authorize surgery, food, or water for the child.” Nurses at the hospital initiated legal proceedings to override the parents’ decision. However, the Indiana Supreme Court ruled that the parents had the right to follow the obstetrician’s recommendation. “Baby Doe” died when he was six days old, before the United States Supreme Court could hear an appeal.

The Reagan Administration argued that this was a case of discrimination based on disability. If the courts agreed, hospitals that refused to treat newborns with disabilities in the future could be denied federal funds under Section 504 of the Rehabilitation Act. A refusal to perform surgery to reconnect the esophagus of an infant with Down Syndrome constitutes disability-based discrimination because an infant without Down Syndrome undoubtedly would be treated and corrective surgery performed. However, the courts did not agree with the administration’s position. (Bagenstos, 2006, p. 430)

New York Baby Jane Doe

The second “Baby Doe” case began in 1983 when a girl with spina bifida was born at University Hospital in Stony Brook, New York. Her parents chose not to allow corrective surgical procedures that “were likely to prolong the infant’s life, but would not improve many of her disabling conditions, including her anticipated developmental disabilities.”

A private citizen initiated a lawsuit to challenge the parents’ decision to deny treatment. The appeals court agreed that the court had the right to review the decisions of parents about medical care. However, it also decided that state power should not be used to reverse the decision in this case. The court found that the decision not to do surgery was acceptable because the treatment was not designed to bring about the child’s death. The court determined that the decision was “in the best interest of the child.” Baby Jane Doe’s spinal abnormality closed on its own and her parents eventually permitted treatment to reduce her hydrocephalus. She was still alive in 1986. (Minow, 1990, p. 329)

The U.S. Department of Health and Human Services also took legal action in the Baby Jane Doe situation and based its arguments on discrimination due to disability. Again, it used discrimination based on disability as grounds. The Second Circuit Court of Appeals ruled that the baby's treatment was not discriminatory because the condition to be treated was directly related to the condition that made her disabled.

The Reagan Administration notified hospitals that Section 504 of the Rehabilitation Act governed the treatment of people with disabilities. The Department of Health and Human Services then issued regulations that required the hospitals to post public notice that said withholding medical treatment for newborns with disabilities violated Section 504 and suspected violations should be reported to a telephone hotline maintained by the Department. If a reported violation proved true, the health facility would no longer receive federal funds.

Many health care providers thought these rules were too intrusive and initiated a lawsuit that eventually reached the U.S. Supreme Court. In 1986 the Court ruled that Section 504 did not authorize governmental intervention when the decision to withhold treatment was made by a parent, rather than the health care provider receiving federal funds.

In *Bowen/Heckler v. American Hospital Association, 476 U.S. 610 (1986),* an amicus brief was filed that summarized the disability issues:

> *First, they contended that the decision to withhold treatment from an infant with a disability is often based on an erroneous, if not prejudiced, understanding of the "quality of life" experienced by individuals with disabilities… Second, the disability rights groups urged that it was the physicians' biases, and not an unconstrained exercise of parental choice, that led to the withholding of treatment from newborns with disabilities. The briefs argued extensively that parents' decisions to withhold treatment from their disabled infants cannot be understood as free choices.* (Kindred, 1976, p. 431-432)

Nat Hentoff gave the issue national prominence in a 1986 article in *The Atlantic Monthly*. He described how he came to link abortion with the Baby Doe cases.

> *For me, this transformation started with the reporting I did on the Babies Doe. While covering the story, I came across a number of physicians, medical writers, staff people in Congress and some members of the House and Senate who were convinced that making it possible for a spina bifida or a Down syndrome infant to die was the equivalent of what they called a "late abortion." And surely, they felt, there's nothing wrong with that…. The simple "fact" that the infant had been born, proponents suggest, should not get in the way of mercifully saving him or her from a life hardly worth living. At the same time, the parents are saved from the financial and emotional burden of caring for an imperfect child.*

While these cases moved through the courts, the Reagan Administration pushed for changes in federal child abuse legislation. President Ronald Reagan signed the Child Abuse Amendments of 1984 (P.L. 98-457) into law in October 1984. These amendments required state child protection agencies to develop mechanisms to intervene on behalf of infants born with life-threatening conditions but who may not be receiving medical treatment and other care. Hot lines were set up so that suspected instances where medical care was being withheld could be reported anonymously. The Act also established priority adoptions for these infants with life threatening conditions.

The Child Abuse Amendments also established the National Information Clearinghouse (NIC) for infants with disabilities and life-threatening conditions. The NIC was reauthorized in 1988. In 1990, the clearinghouse reported on the extent to which state child protection agencies had developed the required mechanisms. The report noted:

- Some states have actively instituted policies, procedures and training to identify and respond to reports of medical neglect of infants with disabilities… Unfortunately, this appears to be the exception, not the rule. Many states have done nothing. Even though federal funds were available, some states did not apply [for them] and others used the supplemental funds to address more global CPS [Child Protection Services] concerns. The belief continues that the problem of medical neglect of infants with disabilities really does not exist, especially in the context of more overwhelming CPS concerns.

- Although the actual numbers of reported cases and the number of cases identified by the Clearinghouse were small, withholding appropriate medical treatment from infants born with disabilities solely on the basis of disability still occurs.

- A major factor in the decision to treat or not to treat appears to be the financial resources of the parents. In many cases, treatment is refused or stopped and families are told to take their child home because of financial concerns.

- An additional issue involves the enforcement, or lack of enforcement, of the Baby Doe Regulations outlined in PL 98-457 and reauthorized in PL 100-294. There is an apparent lack of knowledge of the issues and limited willingness on the part of CPS to investigate cases of potential neglect regarding infants with disabilities. There is little or no training in these issues for professionals who might be in a position to investigate cases (e.g., CPS, police officers and attorneys). It also appears that if the decision is made not to investigate, then the case is not reported. This may help explain the very low number of reported cases of withholding medical treatment from infants with disabilities. (NIC, 1990, p. 42-46)

The Rationale for Withholding Treatment

In September 1989, the U.S. Commission on Civil Rights issued a report, *Medical Discrimination against Children with Disabilities*. The report identified the standards used to make decisions that complied with the Child Abuse Amendments. It also identified the standards being used in actual practice.

The Commission summarized the standard of care as follows:

> *First, all such disabled infants must under all circumstances receive appropriate nutrition, hydration and medication.*
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> *Second, all such disabled infants must be given medically indicated treatment.*
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> *Third, there are three exceptions to the requirement that all disabled infants must circumstances in which treatment is not considered "medically indicated." The exceptions are 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.* (U.S. Commission on Civil Rights, 1989, p. 7)

Based on its inquiry, the Commission said that it had no doubt “that newborn children have been denied food, water, and medical treatment solely because they are, or are perceived to be, disabled.” It suggested that economic considerations and quality of life assessments were major factors in decisions to withhold treatment.

The U.S. Commission on Civil Rights dismissed withholding treatment for economic reasons stating:

> *Today, the real economic costs associated with disability are less a function of the disability or its severity than of a policy that tends to segregate and isolate, at enormous public cost, persons considered most severely disabled. The assumption has been that the severity of the disability is the major determinant of lifetime cost and, consequently, that the more severely disabled a child may appear to be at birth, the less likely it is that the child will be able to contribute as an adult to his or her own economic sufficiency. This assumption is a self-fulfilling prophecy: a diagnosis of severe disability leads to placement of a person in an institutional and nonwork environment that significantly limits that person's capability and entails far more expense than necessary… The Commission emphatically rejects the view that lifesaving medical services should be provided or denied to any group of people based on their estimated economic worth to society.* (U.S. Commission on Civil Rights, 1989, p. 4)

On the issue of quality of life assessments, the Commission concluded:

> *The arguments typically advanced to support denial of lifesaving medical treatment, food, and fluids based on disability are often grounded in*

> *misinformation, inaccurate stereotypes, and negative attitudes about people with disabilities… To accept a projected negative quality of life for a child with a disability based on the difficulties society will cause the child, rather than tackling the difficulties themselves, is unacceptable. The Commission rejects the view that an acceptable answer to discrimination and prejudice is to assure the "right to die" to those against whom the discrimination and prejudice exists.*
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> *The Commission received extensive testimony documenting the possibilities that people with disabilities can have when barriers to their full integration are decreased, adequate access is established to education and employment, and pessimistic prognostications are not permitted to become self-fulfilling prophecies. Research indicates that a negative parental attitude tends to change over time, with increased interaction with the child….*
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> *A substantial body of evidence shows that time and time again predictions of a poor quality of life made at birth for a child with a disability are subsequently proven wrong.* (U.S. Commission on Civil Rights, 1989, p. 3)

Oklahoma Children's Memorial Hospital created a formula to determine the potential quality of life for a child born with spina bifida. This formula was used to determine the level of treatment the infant should receive. The Hospital applied its Quality of Life Assessment protocol between 1977 and 1982.

> *Infants born with spina bifida were evaluated by a "myelomeningocele team" shortly after birth. In this evaluation, the team members wrote, they were "influenced" by a quality of life formula: QL = NE X (H+S). In this formula: QL is quality of life, NE represents the patient's natural endowment, both physical and intellectual, H is the contribution from home and family, and S is the contribution from society.*
>
> *Based on the assessment, the team recommended to the parents that the infant be given either vigorous or supportive care. Vigorous care involved, at a minimum, closing the spinal lesion. Supportive care, by contrast, consisted of a "regular follow-up...until death or until a decision to treat the child more aggressively is made." The team members acknowledged that "treatment for babies with identical [degrees of mental and physical disability] could be quite different, depending on the contribution from home and society."*
> (U.S. Commission on Civil Rights, 1989, p. 20)

The team recommended "vigorous treatment" for thirty-six infants. One of these infants later died of unrelated causes; the rest survived. The team recommended "supportive care" for an additional thirty-three infants. The parents of five infants in the latter group rejected the recommendations, and three of these infants survived. Several other infants survived without treatment for several months and were subsequently treated. The remaining twenty-four infants who received supportive care died. (*Johnson v. Thompson*, Tenth District Court of Appeals, 1992)

The hospital, now known as Children's Hospital of Oklahoma, changed its practice in 1984. Since then, all infants born with spina bifida have received vigorous treatment, with the exception of one infant. In that case, it was clear that treatment would have been "futile." This determination was consistent with exceptions identified in the Child Abuse Amendment.

In 1985, the American Civil Liberties Union and the National Legal Center for the Medically Dependent and Disabled filed a suit on behalf of Carlton Johnson, one of the children affected by the Hospital's denial of treatment. *Johnson v. Thompson* alleged that the hospital had violated the infants' rights under the U.S. Constitution and Section 504 of the Rehabilitation Act.

In 1992, the Tenth District Court of Appeals supported an earlier district court ruling that the rights were not denied. The Tenth District Court agreed with the decision in *Bowen (*476 U.S. at 640, 106 S.Ct. at 2118) that "nothing in the legislative history... even remotely suggests that Congress contemplated the possibility that 'Section 504 could or would be applied to treatment decisions involving defective newborn infants.' "

(see http://www.mnddc.org/parallels2/one/sidebar/054a.htm for Tom Nerney's reflections on this point in history)

Much has changed, much has stayed the same

Much has changed in the quarter century since the Baby Doe cases of the 1980s came to the public's attention. Unfortunately, much also remains the same. Treatment continues to be withheld from newborns. Approximately 60% of deaths in pediatric intensive care units follow limitation or withdrawal of life-sustaining treatment. (Garros, et. al., 2003)

In the past 25 years, major developments in the field of prenatal diagnosis have improved medical care and outcomes for infants born with disabilities. In 1985, few parents knew if their children would be born with severe disabilities. Today, most severe disabilities are identified before the child is born, thanks to advances in prenatal screenings and diagnostic tests. This knowledge allows the parents to arrange to give birth in a major medical center with access to better treatment. In some cases, the parents may opt to terminate the pregnancy based on the results of the prenatal screening. Developments in assisted reproductive technologies have resulted in an increased number of multiple births and a corresponding increase in the number of children born prematurely or with a low birth weight. Low birth weight remains a major issue, and the age at which a newborn has a chance of survival is getting younger and younger. (Mercurio, 2009)

Another important change is the prevalence of Ethics Committees in medical facilities. Such committees were rare in 1985 but are common in hospitals today. Nevertheless, the medical and ethical communities are divided on how to respond to a parent's preferences to resuscitate or not resuscitate babies in distress. The debate revolves around four issues:

- The extent to which medical professionals should act on their professional knowledge.
- The extent to which parent preferences should hold sway.
- The extent to which the financial and emotional "burden" placed on a family should be taken into account
- The most effective way to determine a response that is in the best interests of the child.

A number of studies have attempted to develop statistical models that predict the survival of low birth weight neonates. Currently, data on low birth weight children born in National Institute of Child Health and Human Development Neonatal Research Network centers is being pooled in hopes of predicting survival and disability so that medical personnel can provide families with a more specific prognosis. However, the pitfalls associated with the Oklahoma Quality of Life formula of the early 1980s are a reminder of the dangers that accompany oversimplification. The following cautions are part of the current considerations:

> *Prediction of death is limited even with sophisticated statistical methods such as logistic regression and nonlinear modeling techniques such as neural networks. The difficulty of predicting death should be acknowledged in discussions with families and caregivers about decisions regarding initiation or continuation of care. (Ambalavanan, 2005)*
>
> *Physicians underestimate survival and freedom from handicap in preterm infants. Underestimation of outcome is associated with restriction in the use of appropriate interventions. (Morse, et. al., 2000)*

As life-sustaining technology becomes increasingly available, parents of children with severe disabilities have begun to demand medical treatments that doctors believe will have no beneficial effect. The concept of "medical futility" encompasses treatments that may do no harm, but also are thought to do no good. While the American Medical Association does not recognize the concept of "medical futility," it does insist that patient or parent demand does not mean that a physician has a duty to treat. No physician is obligated to administer treatment that he or she believes does not benefit the patient. (Jordan and LeBlanc, 2001)

The American Academy of Pediatrics, however, supports the "futility" concept.

> *The American Academy of Pediatrics (AAP) has stated that it supports allowing the withholding and withdrawing of a medical intervention when the projected burdens of the intervention outweigh the benefits to the child. The AAP has also stated that treatment decisions regarding an infant should be based on the judgment that the infant will derive net benefit, concluding that medical treatment that is judged to be harmful, of no benefit, or "futile" is inappropriate and should*

> *not be offered or provided. Although decisions about withholding or withdrawing treatments when death is at hand are difficult, a broad consensus has emerged that decisions to withhold or withdraw medical interventions are ethically and legally acceptable in many circumstances, and these decisions fall within the authority of parents or guardians in consultation with the child's physician.* (Diekema and Botkin, 2009)

The 1999 Texas Advance Directives Act, or Futile Care Law, allows a health care facility to discontinue life-sustaining treatment against the wishes of the patient or guardian. Treatment can be discontinued ten days after the patient or guardian gives written notice that continuation of life-sustaining treatment is considered medically inappropriate by the treating medical team. The decision must be reviewed and approved by an Ethics Committee before any action is taken. Since the Act was put into effect in 1999, treatment has been withheld from both infants and adults.

In 2002, President Bush signed the Born Alive Infants Protection Act (H.R. 2175). The Act says that every infant who is born alive – including an infant who survives an abortion procedure – is considered a person under federal law. According to Bush, the Act "establishes a principle in American law and American conscience: there is no right to destroy a child who has been born alive. A child who is born has intrinsic worth and must have the full protection of our laws."

More than a decade into a new millennium, the controversy continues.