**STUDY NOTE**

**ELECTIVE SURGERY—WHEN PARENTAL AND MEDICAL OPINION SUPERSEDES A CHILD’S RIGHT TO CHOOSE**

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**I. INTRODUCTION—TAKING AWAY A CHILD’S CHOICE**

In *Raising a Woman*, Mary was fourteen when she had an operation that would forever deprive her of the ability to bear a child. In facing this surgery, she had no choice in the matter, no option to say no, and no advocate asking what she wanted. She was alone and left without a voice because her physician, and even her own mother, had taken her choice away. When Mary received a hysterectomy, her mother’s needs were addressed—the monthly anguish in caring for her daughter’s menstruation was eliminated, thereby diminishing the extremely difficult turn that her life had taken in raising a daughter with Cerebral Palsy. But Mary was left empty. It was not a medical necessity, nor would it serve to benefit Mary directly. Instead, the surgery would benefit those that aided Mary in her daily activities. Nonetheless, it was Mary who paid the price for this moment. Alone, without a voice, and choiceless in a doctor’s treatment or mother’s care, Mary forever lost her ability to bear a child, the weight of which fundamentally effects her to this day, decades later.

This Note explores a minor’s choice in regards to medical decision-making. Although a short excerpt includes information about minor’s general right to consent, the majority of the article focuses on a minor’s right to refuse treatment. The Note begins with a brief history of the law surrounding medical care for children with disabilities, and offers parallel examples that demonstrate Mary’s predicament through a discussion of different types of elective medical care. Next, the Note focuses on minor’s right to refuse treatment, a doctor’s duty to her patient, and lastly a parent’s duty to her child.

**II. A BRIEF HISTORY**

The history surrounding medical care of children with disabilities is complicated, and for the most part deals with courts and legislatures disagreeing


1 Mary Stainton, *Raising a Woman*, 296 J. AM. MEDICAL ASS’N. 1445, 1445 (2006). This previously published article was edited, and performed at the Telling Tales on Families Monologue Performance.
about parent- and physician-choice and the legislature’s aim to protect disabled children. The divide remains, and this section briefly describes the struggle.

The fight over protecting children with disabilities from medical mistreatment began with litigation surrounding Section 504 of the Rehabilitation Act of 1973. Although that statute did not specifically protect children in medical cases, the act did protect disabled people in general and proscribed any form of discrimination based upon a disability. In the first piece of litigation interpreting this act, the court held the statutory language did not protect a newborn child (“Baby Doe”) whose physicians allowed him to starve to death because he was born with Down syndrome. The backlash from this ruling reached the executive and legislative branches of the federal government. President Reagan directed the Secretary of Health and Human Services (HHS) to notify health care providers that section 504 applied to Baby Doe situations, and new regulations were passed by the legislature. The courts subsequently invalidated these actions, however, because they found them to be “arbitrary and capricious.” Congress and the executive branch responded again by clarifying the statute and implementing new regulations to protect children with disabilities, only to be struck down again by the federal court system. In American Hospital Association v. Heckler, the Second Circuit Court of Appeals held that “section 504 could not prevent the medical neglect of a handicapped newborn because the section did not refer to treatment of a handicapped newborn.” The Supreme Court later affirmed this decision in a plurality opinion.

Finally, Congress and the executive branch implemented The Child Abuse Amendments of 1984 creating new rules and regulations in the area. These amendments conditioned providing federal funds to a state on that state’s implementation of rules prohibiting discrimination against disabled children, and offered investigative procedures and legal remedies to prevent neglect. Another body of law developed to prevent discrimination to those living with disabilities was the Americans with Disabilities Act (ADA). Although the ADA fails to
address medical care for children, it does clarify that “discrimination based upon a
disability or handicap is intolerable.”

Although the federal government has been unsuccessful at passing legislation
that withstands the scrutiny of the federal courts, the executive and legislative
branches have circumvented this problem by empowering states to create such
legislation. By conditioning federal funding on the basis that a state protects
disabled children, the federal government has begun to create meaningful change
in this area of law.

III. ELECTIVE MEDICAL TREATMENTS FOR CHILDREN WITH DISABILITIES

Mary’s story of being forced to undergo medical treatment without her
consent is not unique, and although not specifically addressed by the federal
government, there are a number of disabilities that often prompt controversial
medical procedures on children in the same manner. Like Mary’s hysterectomy,
these procedures serve non-medical needs and are performed without the consent
of the patient. This section gives examples and preliminary information regarding
these treatments.

The first example is cochlear implants. The implant is a small device that may
be surgically placed under a deaf child’s skin that allows them to have a “useful
representation of sounds in the environment and help him or her to understand
speech.” However useful it may be, the device is not medically necessary and is
highly controversial in the deaf community. A second example is cosmetic
surgery for children with Down syndrome. Although medically unnecessary, it is
becoming more popular for parents to use cosmetic surgery including tongue,
eyebrow, and eyelid reshaping in order to hide the visual cues of Down syndrome
in their children. Other examples include surgery for children born with

15 Uddo, supra note 2, at 304.
16 NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS,
Cochlear Implants, http://www.nidcd.nih.gov/health/hearing/coch.asp (last visited Apr. 21,
2009).
17 See Robert L. Burgdorf, Restoring the ADA and Beyond: Disability in the 21st
Century, 13 TEX. F. ON C.L. & C.R. 241, 324–25 (2008) (this article discusses a case from
Michigan where a court-appointed advocate charged a deaf mother with neglect after she
refused to consent to cochlear implant surgery for her two deaf children. The court
ultimately held the mother had the right to deny cochlear implants to her deaf children. The
article explains the deaf community’s feeling that cochlear implants are inadequate and a
force of destruction to deaf culture. Burgdorf quotes a former Gallaudet University
president in saying, on behalf of people who are deaf, that “we hold in common this
resentment of efforts to fix us.”).
18 See generally Ann K. Suzedelis, Adding Burden to Burden: Cosmetic Surgery for
Children with Down Syndrome, 8 VIRTUAL MENTOR 538 (2006), available at
http://virtualmentor.ama-assn.org/2006/08/oped1-0608.html; see also National Down
ambiguous genitalia, administration of psycho-altering medications, authorization of child organ donation, and forcing children into controversial and medically unnecessary therapy options such as reparative therapy which aims to change a child’s sexual orientation. All of these examples deal with non-medically necessary treatments for children. Most have major impacts on a child’s future well-being and the direction of their future adult life. Lastly, as in Mary’s case, each of these procedures is generally completed with only the consent of the parent, leaving the patient-child choiceless in the decision.

IV. THE LAW

A. A General Overview of a Child’s Ability to Consent to Medical Treatment

Although each person generally maintains the right to consent to their own medical treatment, this right in children is diminished by the child’s lack of competency. This section will briefly discuss a child’s right to consent and the prevailing interests of the state and parents (who may invoke this right or take it away).


20 See Jennifer Albright, Comment, Free Your Mind: The Right of Minors in New York to Choose Whether or not to be Treated with Psychotropic Drugs, 16 ALB. L.J. SCI. & TECH. 169, 170 (2005); Amanda Slater & Ronald E. Reeve, The “Tug-of-War” over Attention-Deficit Hyperactivity Disorder: Balancing the Interests of Parents and Schools (And Don’t Forget the Kids), 27 DEV. MENTAL HEALTH L. 1, 1 (2008).


22 Sarah E. Valentine, Queer Kids: A Comprehensive Annotated Legal Bibliography on Lesbian, Gay, Bisexual, Transgender, and Questioning Youth, 19 YALE J.L. & FEMINISM 449, 457 (2008) (giving a detailed account of how these programs are sold to parents despite their devastating impacts on children); see also JASON CIANCIOTTO & SEAN CAHILL, NAT’L GAY & LESBIAN TASK FORCE, YOUTH IN THE CROSSHAIRS: THE THIRD WAVE OF EX-GAY ACTIVISM 71 (2006), available at http://www.thetaskforce.org/downloads/reports/reports/YouthInTheCrosshairs.pdf (this report discusses conversion therapy in detail, finding that “parents are being told that homosexuality is a mental illness, caused primarily by their inability to parent properly.” Id. The treatment for such illness, which parents consent to on behalf of their children, often includes shock therapy or emetics to induce the child into vomiting).
In medical cases dealing with children, there are at least two competing interests—the parent’s rights and duties to protect and care for their child, and the child’s right to privacy and freedom of choice over their own body. For the most part this balancing act takes place on the state level where legislatures may develop statutory language that designates rules. The legislation is often based on the minor’s competency to make medical decisions. However, minors are generally found to “lack the requisite capacity to make decisions for themselves concerning their own medical treatment.” Therefore, the general rule is that “a minor does not have authority to consent to medical treatment. A healthcare provider must obtain the informed consent of an adult who is authorized under state law to act on behalf of the minor for purposes of making healthcare decisions.” Although parents have a right to protect and care for their children in the manner they see fit, there are various state-recognized exceptions. These exceptions protect the state’s interest in caring for children, which may supersede the parent’s rights in extreme situations. The exceptions may apply to emancipated minors, mature minors, or in sensitive and/or high-risk conditions or procedures.

In cases dealing with sensitive or high-risk procedures, the state may step in to protect the child from parent’s and doctor’s decisions. “[T]he state often has the power to limit parental freedom and authority when parents endanger the welfare of children . . . [the state exerts this authority] to protect those members of society who are unable to protect themselves.” In addition, the state may intervene where the parent has an emotional conflict that has impaired their ability to make a decision based on the best interest of the child (for example, when a conflict of interest arises because a parent offers to donate one child’s organs to save the life of their other child). Another situation that may require state intervention is “when a treatment decision interferes with an individual’s rights and interests,” such as the right to procreation or the right to be free from sterilization. In Mary’s case, under these modern rules, both the conflict of her mother’s interest as well as the strict rules now placed on reproductive rights would certainly be factors in determining whether Mary’s mother or doctor conducted themselves unlawfully by consenting to and performing the hysterectomy.

These exceptions, however, are rarely invoked in the controversial situations discussed in this paper as the state rarely steps in to prevent such procedures.

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25 Id. at 671; see also In re E.G., 549 N.E.2d 322, 327 (Ill. 1989) (holding that a minor could refuse a blood transfusion if found to be “mature”).
26 Hawkins, supra note 23, at 2084–85.
27 Lareau, supra note 19, at 145.
28 Id. at 144–46 (discussing the highly pertinent right to procreate and the rule against sterilization).
Instead, the state’s power is generally used only to compel lifesaving procedures when a parent refuses to do so, or to allow a minor to consent to treatment on their own for issues relating to venereal diseases, mental health, or reproductive treatment. In these situations, the state is either protecting the life of the child or protecting the state’s interest in preventing contagious diseases, mentally unstable citizens, or unwanted pregnancies. Therefore, although the state may step in for some of the controversial topics discussed herein, the fact is that they generally do not. The decision is more often left to the parents and child, and because the child is generally found to lack the ability to consent, the decision remains solely in the hands of the parents, leaving the child without choice in the matter.

B. A Doctor’s Duty to Her Patient

The issue of who should be eligible to consent to treatment on behalf of a minor raises interesting questions when compared to a doctor’s rights and duties to her patient for proper care and confidentiality:

Legal compliance is important because failure to obtain effective informed consent may give rise to a cause of action for battery based on healthcare provider’s intentional and unconsented touching of the patient. Additionally, failure to obtain effective informed consent may breach the fiduciary duty that a physician owes to her patient and give rise to a malpractice action.  

Generally, where there is no emergency, a medical practitioner must obtain consent of the patient or, where the patient is not competent to give consent (as is generally the case with minors), the practitioner must gain consent from a legally authorized agent. A physician may respect the consent of a minor who is found to be emancipated or mature. In addition, a physician may accept the consent of the state where there is a court order that deemed state intervention necessary to protect the best interest of the child. Therefore, although physicians must protect themselves from performing a procedure on a patient that has failed to consent (in addition to protecting the confidentiality of that patient), in most cases, unless the state intervenes or the minor has been emancipated, physicians are protected only by the consent of the parent.

30 See Vukadinovich, supra note 24, at 668.
C. A Parent’s Duty to Her Child—Neglect vs. Abuse

A parent’s duty to her child has two competing elements. The first is the deference that the government pays to parents in raising their children. “Decisions of the Supreme Court throughout the twentieth century have granted constitutional protection to parents’ rights to rear and educate their children.”\(^{32}\) The state, however, has a competing interest and may impose liability against parents who neglect or abuse their children.\(^{33}\) “Parents may face prosecution for neglect or abuse if they do not seek out and obtain necessary medical care for a minor child.”\(^{34}\) Therefore, it is a generally recognized rule that a parent has a legal duty to seek proper medical attention and care for their minor children.\(^{35}\) In extreme cases, courts have held that a parent’s failure to provide adequate medical care was the proximate cause of death in a homicide prosecution.\(^{36}\) Therefore, while parents do have a broadly-recognized right to parent in the manner they see fit, courts have found that states may usurp those rights in certain situations because parents also have a duty to provide adequate medical care in the best interest of the child.

V. DIFFICULTIES IN ADDRESSING THE PROBLEM

The law surrounding a child’s right to refuse treatment for the controversial procedures discussed in this Note is complex. The area is complicated by the many interests involved including those of parents, doctors, states, and of course children. In addition, this area of the law is likely underdeveloped with regards the technical difficulties of bringing actions in such cases. In Mary’s case, for example, she is highly unlikely to ever bring an action against her mother who, while making a devastating decision in Mary’s opinion, did the best that she could in a difficult situation. Mary understands this and has reconciled her frustration with her mother’s decision through her mother’s apology and Mary’s love for her mother. Therefore, cases are rarely brought in these situations.

In addition, statutes of limitation may prevent the courts from ever addressing actions brought by children against their parents for over-reaching medical authorizations. In most of the examples given, the treatment is authorized when the child is very young and it is not until years, if not decades later, that the child realizes the extent of the harm that was done.\(^{37}\) These cases may, therefore, often

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32 Hawkins, supra note 23, at 2080 (offering many cases which stand for the proposition that courts must allow parents to rear their children the way they see fit).

33 See Vukadinovich, supra note 24, at 671.

34 Id.

35 Baruch Gitlin, Annotation, Parents’ Criminal Liability for Failure to Provide Medical Attention to Their Children, 118 A.L.R. 5th 253 § 2(a) (2004).

36 See id at § 11.

be barred by the statute of limitations for actions like battery, neglect, or breach of confidentiality.\textsuperscript{38}

Because of the limitations on bringing an action of this nature in court, it is more likely that these issues should be solved on a legislative level. States can take it upon themselves to create a statutory scheme that more adequately addresses the interests involved and seeks to protect children from overzealous parents and medical advisors. States or organizations such as the Down Syndrome Association (which opposes cosmetic surgery for the purpose of hiding visual cues of the condition) could benefit from non-legal remedies. Such options may include advocacy or educational campaigns that reach both parents and medical practitioners. These campaigns could educate decision makers about the long term effects of these procedures on children, both physically and emotionally. They could also help to open the discussion of the many rights and interests that are involved and diminish hasty decisions that are based solely on one party’s interest.

Therefore, although the law in this area may not develop through the courts, due to the limitations on bringing such cases—including the influence of familial relationships and statutes of limitation—there are alternative methods of meliorating children’s welfare in these cases. First, legislative action should create rules and regulations which protect children from narrow-sighted parents or physicians. Second, education and advocacy on behalf of minor children should help to expose the weight of these decisions and how they may effect the children’s future adult lives.

\textbf{VI. CONCLUSION}

Although this paper fails to address the full scope of remedies available, the law should seek to protect children from those who are able to consent on their behalf. Hysterectomies, cochlear implants, organ donation, cosmetic surgery for children with Down Syndrome, genital reconstruction, and reparative therapy all have long lasting effects that will stretch into a child’s adulthood. Therefore, the repercussions of these decisions must be taken very seriously where a person’s life is to be altered without their consent.