

**PARENT-CHILD DISAGREEMENT IN PEDIATRIC MEDICAL
DECISION-MAKING**

An Undergraduate Research Scholars Thesis

by

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ABSTRACT

Parent-Child Disagreement in Pediatric Medical Decision-Making

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Literature Review

Decision-making in pediatric medicine is the subject of an extensive body of literature in biomedical ethics, of which the vast majority concerns conflict between parents and clinicians. Such conflicts may arise when parents refuse to comply with medical recommendations due to religious or other personal beliefs. Many papers advise clinicians on how to delicately navigate their relationships with their patients' parents so as not to jeopardize child-patients' access to medical care. Little has been said about disagreements between parents and children. Such conflicts may be rare, but when they occur, parents are legally entitled to override their children's preferences. This may have grave consequences for ill children whose parents refuse to seek out medical advice or treatment on religious grounds, for children with terminal or lifelimiting illnesses whose parents refuse to honor their preferences for end-of-life care, and for children who are unable to receive vaccinations or other preventative care without parental consent. No theoretical argument can justify prioritizing parental religious freedom or right to parental authority over the human right to bodily autonomy.

Thesis Statement

Children have the capacity to form and the right to pursue personal values, especially in the context of their own healthcare. It is only when children's preferences for their medical treatment undermine their self-professed values that their decisions may be justifiably overridden by parents or healthcare providers.

Theoretical Framework

The formal discipline of bioethics draws heavily on legal and political scholarship, but the arguments presented in this thesis are conducted at more fundamental, philosophical level.

Project Description

Respect for patient autonomy is a fundamental principle of biomedical ethics. However, it holds relatively little weight in pediatric medicine, in which parents act as proxy decisionmakers for their children. Challenges to this sort of parental authority have focused on parent/clinician disagreement, without recognizing children as individuals who may – and often do – have opinions about their own healthcare. The most compelling arguments for granting parents decision-making authority instead of doctors focus on their unique ability to understand their children's desires and interests. Clearly, arguments that parents should have a right to overrule their children's decisions would need to be supported by different means. Because the law gives parents authority over their children's medical care by default, few appear to have felt it necessary to justify the practice. The primary goal of this project is to demonstrate that allowing parents to overrule their children's medical decisions is, for the most part, unjustifiable. Following a critical examination of the assumption that parents have an inherent right to make decisions on their children's behalfs, I compare the standards used to evaluate decisional capacity in children and adults. After finding that the capacity and competence of children is severely underestimated relative to that of adults, I present several positive arguments for

extending decisional authority to children in the realm of their own healthcare. I conclude by acknowledging that because children develop various cognitive capacities asynchronously, parents may consent to some treatments on their children's behalf, if and only if that treatment is the most consistent with the child's self-professed interests.

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INTRODUCTION

Of the four classic principles of medical ethics – beneficence, nonmaleficence, respect for autonomy, and respect for justice – respect for patient autonomy is recognized as being “first among equals.”¹ Paternalism has fallen out of style; now, autonomy is honored even when patients would exercise it in a way contrary to their best interests. This is especially true in the United States, given the country’s privatized healthcare system and highly individualistic culture.

Autonomy does not have the same status in pediatric medical ethics, in part because children are born completely nonautonomous and gradually develop the capacities needed to exercise autonomy at a unique pace.² In some ways, the dynamic of pediatrics resembles veterinary medicine, with a triadic relationship among patient (child/animal), client (parent/owner), and doctor. Such relationships can be difficult for clinicians to navigate if they feel the wishes of a client/parent are at odds with the best interest of their patient. By default, parents make medical decisions on behalf of their children until they reach the age of majority – typically 18 – with some exceptions.

Currently, an unemancipated 17-year-old in the state of Texas cannot elect to receive a vaccine without the consent of a parent or guardian. A 14-year-old teen parent, on the other hand, has the right to consent to vaccination for herself as well as her child. This illustrates two peculiarities of pediatric medical decision-making: parenthood is recognized as having a special legal and moral status, and ability is not the basis for which legal minors are granted decision-making authority. Parenthood does not make minors inherently more capable of consenting to

¹ Gillon, “Respect for Autonomy First Among Equals”

² Baines, “Medical Ethics for Children”

medical treatment; however, it elevates their moral standing in such a way that withholding decision-making authority from them apparently becomes morally impermissible. The counterintuitive result of this is that adolescents have more dominion over the bodies they conceive than the bodies they inhabit.

Allowing parents so much power over their children's medical care is not only problematic in a theoretical sense: it can and does result in actual harm to children. Ironically, increased emphasis on autonomy has made this phenomenon more frequent, because the accompanying moratorium on paternalism prevents doctors from being able to mitigate the damage by overriding harmful parental preferences. The greatest harm to children occurs when parents withhold their consent for a medically recommended treatment or intervention. One common reason for this is a religious commitment to faith healing. Hundreds of children have died painful, drawn-out deaths from easily treatable conditions, like diabetes and appendicitis, because their parents refused to seek medical care.³ Other treatment refusals are motivated by pseudoscience and conspiracy theories about modern medicine that have flourished in online communities, fueling skepticism and rejection of vaccines and other medical treatments. The resulting decline in vaccination rates has caused outbreaks of preventable diseases like measles and whooping cough. In these scenarios and others like them, children have no alternatives or agency and are left at the mercy of their parents' beliefs.

When considered from the perspective of child welfare, the dangers of unilateral parental authority seem obvious, but legal debates on the subject have adopted a different angle. Parents have defended their control over their children's healthcare as part of their broader rights to autonomy and privacy from state interference. Attempts to prevent parents from ignoring

³ Hughes, "Death by Faith-Based Medical Neglect"

doctors' treatment recommendations have failed because they would reassign decision-making authority to some other governing body. Because the issue has been politicized and conflated with an assault on liberalism, parents are portrayed as defending their families from a tyrannical government. Meanwhile, their children are left out of the picture entirely. A successful defense of parental authority in pediatric medical decision-making would need to honestly acknowledge its cost to child welfare and autonomy.

While rare, disagreements between parents and children in healthcare settings do occur and have the potential to be of enormous consequence. This is especially true in critical and end-of-life care, when parents refuse to honor children's wishes for how they live out their final days. The proper clinical approach in situations of parent-child disagreement has rarely been discussed, and parental authority has not been explicitly championed over child autonomy. Parents may have a legal right to override their children's preferences for their own medical treatment, but I argue that they do not have a moral right to do so.

In this thesis, I will argue that we must acknowledge children as moral agents – as individuals with their own interests. Some minors are already allowed to independently consent to particular treatments in particular circumstances, but I argue that this should be the rule rather than the exception. The first chapter explores the background and justification of parental authority, along with its role in pediatric healthcare. The second chapter reviews some common arguments against giving children control over their own medical treatment, finding we hold children to a different, higher standard than we do adults when evaluating decisional capacity. The third and final chapter discusses several positive rights-based and utilitarian reasons to give children more say in their own medical treatment.

CHAPTER I

CURTAILING PARENTAL PURVIEW

Parental rights are given moral and legal significance far beyond what they contribute to children's welfare. Child abuse and neglect laws in a multitude of states include religious exemptions to protect the right of parents to practice their religious beliefs, even if they endanger their children by doing so.⁴ Parental authority in pediatric medical decision-making is justified both implicitly and explicitly on the grounds that parents are uniquely qualified to make better decisions for their children than doctors because of their unique insight into their children's personalities and needs. However, this cannot explain why parents are more qualified than the child-patients themselves to make such decisions.

The first part of this chapter details how prevailing notions of parenthood have changed over time. The second part of this chapter discusses several contemporary theories of parenthood and proposes a definition more in line with our 21st century sensibilities. The third part demonstrates that parental rights and authority, no matter how they are conceived, cannot justify parents overruling their children's preferences for treatment. The fourth section discusses the role of parents in pediatric medical decision-making specifically. I ultimately find that parents have no claim right to make decisions about their children's medical care, and that they only continue to feel entitled to do so because they are the most qualified decision-makers in the earliest years of their children's lives. This chapter is intended to weaken readers' deeply ingrained convictions about parenthood and family dynamics so they may be more receptive to subsequent arguments in favor of reassigning decisional authority to children.

⁴ Hughes, "Death by Faith-Based Medical Neglect"

Parenthood Throughout History

Many people have strong convictions about the nature of parenthood and the parent-child relationship. As with other beliefs, we may be tempted to take the strength of these convictions as evidence of their truth. However, attitudes about parenting vary widely among cultures and over time. The family values popular in American society have evolved significantly over the past four centuries, shaped by socioeconomic changes, influential philosophical and religious thinkers, and scientific knowledge.⁵

In the early colonial period, religious leaders were the primary source of parenting guidance. Parental attitudes were strongly influenced by the religious beliefs of John Calvin, who advocated “breaking the will” of children. Parents demanded obedience and submission from their children in the hopes of instilling a strong work ethic, as children were expected to contribute to household labor. The need for child labor waned toward the end of the 18th century with increasing industrialization, changing the role of the child within the family. By the early 19th century, previous authoritarian attitudes toward parenthood began to face challenges from the philosophies of political liberalism. John Locke’s conception of the child’s mind as a “tabula rasa,” or blank slate, was particularly influential – rather than being crushed into submission, children were to be nurtured into fulfilling their potential. In the second half of the 19th century and first half of the 20th, manufacturing replaced farming as the most common vocation in the United States, and parents now urged their children to attain additional education in order to obtain a higher socioeconomic status instead of raising them to follow in their footsteps.

⁵ Abramovitz, “Parenthood in America”

Influenced by Jean Jacques Rousseau's conception of children as fundamentally good, parents strove to treat their children with affection and support, shield them from harm, and instill virtues of self-control and self-discipline that had eclipsed obedience and piety in importance.

From 1940 onward, family size decreased considerably as the need for child labor was all but eliminated. Childhood has been prolonged along with education, so parents are now expected to provide for their teenage and young adult children who would have been self-sufficient a mere generation before. Cognitive development and intellectual work are cultivated and encouraged in lieu of technical skill and physical labor. Attempts to define the nature of children in philosophical or religious terms have been largely replaced by the field of developmental psychology. Studies on brain development now inform conventional parenting guidance. An increasingly interconnected society has decentralized the family unit, so that members of a family spend most of their time outside the home and parents must now compete for influence over their children with school, peers, and culture.⁶ A close relationship between parenting strategies and economic structure has remained consistent throughout all stages of parenthood in the United States. Because the functional purpose of parenthood is to raise self-sufficient individuals, the skills and virtues parents have aimed to cultivate in their children have changed with the times.

Parenthood Today

While the concept of parenthood itself is familiar, its necessary and sufficient conditions are the subject of ongoing debate. Identifying these defining attributes is a worthwhile undertaking given the moral, cultural, and legal significance of parenthood in our society. Previous discussions have distinguished natural/original parenthood from social/custodial

⁶ Abramovitz, "Parenthood in America"

parenthood.⁷ The former is relevant in debates about surrogacy, gamete donation, ectogenesis and the like. The latter is concerned with the origin of parental rights and responsibilities. Natural parenthood typically transitions into social parenthood -- this is what happens when two parents decide to raise their biological child -- but not necessarily.⁸ Accounts of social parenthood can fall be classified as either causal or voluntarist accounts, of which several of each are reviewed below.

Causal accounts refer primarily to natural parenthood, meaning they explain parental status in terms of the role of an individual in begetting a child.⁹ This is the attitude of most traditional and religious belief systems. Parents can “cause” their children to exist in a number of ways. Genetic parenthood, which is perhaps the most straightforward account, clearly defines parents as the individuals whose gametes were combined to conceive a child. It implies that biological parents owe something to the child they helped create. Gestational parenthood is similar to the genetic theory of parenthood, but explains parental rights in terms of the intimacy formed between parents and child during pregnancy and delivery.¹⁰ This account was developed after medical technology allowed for procedures like surrogate pregnancy and gamete donation, which have made it theoretically possible for up to three people to be causally responsible for fetal development, as the necessary ovum, sperm, and womb may each belong to separate individuals.¹¹

While they may be attractively straightforward, causal accounts of parenthood fail to capture the nuance that the social concept of parenthood has developed over time. Genetic

⁷ Fuchs, “The Changing Faces of Parenthood”

⁸ Bayne, “Toward a Pluralist Account of Parenthood”

⁹ Porter, “Why to Prefer a Causal Account”

¹⁰ Kennedy, “Ectogenesis and Gestational Motherhood”

¹¹ Magnusson, “Can Gestation Ground Parental Rights?”

parenthood may be the easiest to ascertain, but it is not relevant to social parenthood as it exists in modern families today. Many children are raised by loving parental figures who were not involved in their conception. While a gestational account of parenthood is somewhat more versatile in that it accommodates new reproductive technologies, it fails to explain how the parental rights of fathers could equal those of mothers. A non-biological causal account of parenthood could theoretically attribute parental status to anyone with a role in bringing about a child's existence. This fails to capture our intuitions about parenthood, because while a child may not have been conceived if not for a particular fertility specialist or nagging mother-in-law, their involvement does not seem to justify claims of parenthood. A contemporary criticism of causal accounts of parenthood is that they undermine the defensibility of abortion. Issues of choice and consent are irrelevant in causal accounts of parenthood, which depict parental rights and duties as either beginning with conception or developing over the course of gestation.¹²

Voluntarist accounts of parenthood are founded on the common premise that parental rights and obligations arise from a voluntary acceptance of the parental role. Two varieties of voluntarist theories include intentional and investment theories. The intentional theory of parenthood states that parents are those who developed and carried out the plan to have a child, whether through surrogacy or adoption. The investment theory of parenthood simply states that parents are those who do the work of parenting, and that parental rights are earned in proportion to that work. This theory explains why a noncustodial, genetic parent is not morally or legally entitled to assume joint custody after being entirely uninvolved in a child's life. Voluntarist accounts in general accommodate unconventional family dynamics and honor nontraditional

¹² Bernard, "Breaking the Bond"

parents as equally valid, which makes them appealing to our contemporary sensibilities about family.

Despite their inclusivity, voluntarist accounts of parenthood are unsatisfying in other ways. One of their most characteristic shortcomings is their struggle to explain the existence of parental obligations. If parenthood is a role taken on voluntarily, it stands to reason that it could be voluntarily surrendered in the same way, leaving advocates of voluntarist accounts of parenthood without a way to compel uncooperative parents to fulfill certain duties.¹³

In practice, the people we recognize as parents come by their status in a plurality of ways. Grandparents, stepparents, and adoptive parents raise children who are not biologically their own. Children may have more or fewer than two parental figures in their lives. These dynamics are difficult to accommodate in a single account of parenthood, but the absence of such a unified account weakens attempts to explain parental rights, obligations, and authority.

Parental Rights and Authority

Parents are legally recognized as being in possession of certain parental rights. However, because parenthood is accounted for in so many different ways, the philosophical basis of these rights remains unclear. A closer examination of parental rights reveals that they do not share many of the characteristics essential to rights. There are several ways in which parental rights may be understood, but I will argue that none of them support the right to override a child's choice regarding his or her medical treatment.

Before discussing parental rights, it is helpful to review what we mean by rights in general. Regardless of how they are conceived, "rights" have one common characteristic: they

¹³ Bayne, "Toward a Pluralist Account of Parenthood"

are oriented toward protecting the interest and/or autonomy of their possessor.¹⁴ The “right” of an employer to pay his employees is much more accurately described as the employees’ right to be paid for the work that they do. Therefore, a complete account of any sort of right must include a profile of the rights-bearer. In terms of the example used previously, the specific nature of the employer/employee relationship is far better evidence for the right of employees to be paid than for the right of employers to pay them. Rights can be broadly classified as either claim or liberty rights, which are honored in different ways. Claim rights impose an obligation on others, while liberty rights simply indicate a duty *not* to do something. Your right to park your car, for example, may be either a claim right or a liberty right depending on context. Purchasing a parking permit for space #100 in a privately owned lot gives you a claim right to park in that space; anyone else who parks in space #100 would be violating your rights. In contrast, you have a liberty right to park your car in a public lot, meaning that no one may bar your entry, but if you are unable to do so because every space happens to be occupied, your rights haven’t been violated. Similarly, parental rights may be considered liberty or claim rights depending on what their protection requires of others.

One of the ways the phrase “parental rights” may be interpreted is as the right to become a parent.¹⁵ Arguments that strip people of the right to reproduce based on their fitness have the potential to be weaponized against people with disabilities or other non-favored traits. Matthew Liao argues that biological parenthood should be considered a human right because of the immense value and meaning many people find in parenthood. Given its hypothetical, abstract formulation, the right to parent can be considered a liberty right: adults have the right to be free

¹⁴ Montague, “The Myth of Parental Rights”

¹⁵ Liao, “Biological Parenting as a Human Right”

from reproductive coercion. This is distinct from a parent's claim right to exercise power over a specific child for the purpose of raising them in a particular way. The former liberty right can be defended without necessarily endorsing the existence of parental claim rights.

Parental authority, which can be understood as a claim right parents have to their children's obedience, has been defended in a variety of ways.¹⁶ Child-centered accounts treat parental authority as a tool that empowers parents to act as custodians of their children's best interests. This is the approach adopted by the UN Convention on the Rights of the Child (1990). Child-centered accounts of parental authority demonstrate a moral commitment to equality and self-determination that may clash with traditional moral values like familism and filial piety. Parent-centered accounts of parental authority operate with the assumption that parents have a right to raise their children as they see fit.¹⁷ Like child-centered accounts, they are oriented toward a single individual, but that individual happens to be the parent. Legal rulings in the United States have protected parent-centered parental authority insofar as they allow parents to preserve their culture, religion, or way of life. This kind of parental authority is typically used to justify decisions about children's education, religion, healthcare, and custody. *Meyer v. Nebraska* (1923) and *Pierce v. Society of Sisters* (1925) were two U.S. Supreme Court rulings that recognized parents as having a claim right to determine the upbringing of their children.¹⁸ In most court cases, parents must be specifically proven *unfit* to exercise such control before courts will make decisions to suspend or eliminate parental rights based on the children's best interests. Family-centered accounts of parental authority do not promote the good of any one individual, but of the family unit as a whole. A traditionalist perspective is that because parental authority is

¹⁶ Engelhardt, "Four Views of Family"

¹⁷ Howe, "Do Parents Have Fundamental Rights?"

¹⁸ Bell, "Children Are People"

essential to maintaining a family unit, it is a good worth preserving even at the expense of an individual family member's best interest or autonomy. The rights and obligations of each family member arise from their specific role in the family, as mother, father, child, and so on. Confucian and traditional Christian belief systems, in particular, consider obedience and deference to parental authority to be fundamental obligations of children.¹⁹

A child-oriented account of parental authority is intuitively appealing to those who conceive of the parent-child relationship as fundamentally based on the commitment of parents to promoting their children's best interests.²⁰ This characterization of parenthood implies that parental rights and authority are only worth protecting insofar as they allow parents to fulfill their duties. However, it is unclear how parental claim rights or authority *could* be justified in terms of children's best interests, given that rights are necessarily oriented toward their possessors. Any feature of the parental role intended to promote the welfare of children would be more accurately understood as a parental obligation. At best, parents might have a half-liberty right to choose how to go about fulfilling their obligations, meaning they have no liberty *not* to do so and no claim right that allows them to insist on fulfilling this obligation in one particular way. Take, for example, the parental obligation to see to the education of one's child. Parents may have a liberty right to choose between sending their children to public or private schools to fulfill this obligation. This "right" does not mean that they are entitled to opt out of educating their children or that they have a right to "educate" their children at home by setting them in front of a television for eight hours a day and insisting that they've fulfilled this obligation by doing so. This can be similarly applied to medical decision-making. Parents have the obligation to monitor

¹⁹ Engelhardt, "Four Views of Family"

²⁰ Gheaus, "Children's Vulnerability and Legitimate Authority"

and protect their children's health, and may choose which pediatrician to visit, which treatments to undertake to address a specific issue, and so on. They cannot refuse to address their children's health issues at all, and do not have the right to insist that treatments proven to be ineffective, like faith healing or homeopathy, be recognized as a fulfillment of their obligation. Because "health" is experienced subjectively, the perspectives of children are essential in determining whether parents have met this particular obligation. For these reasons, child-centered accounts of parental authority are trivial – any action they permit could be justified more simply in terms of children's wellbeing.

A parent-oriented account of parental rights and authority is more compatible with our general understanding of rights than a child-oriented account. However, it conflicts with some of our intuitions about the nature of parent-child relationships. To recognize parents as having a claim right to exercise power over their children is to position children as the property of their parents; as passive elements to be manipulated and arranged in service of someone else's vision.²¹ I take the moral reprehensibility of this dynamic to be fairly self-evident, given that it places no clear limitations on parental authority that would act as safeguards against abuse or neglect. Parent-oriented accounts of authority are also weakened by theoretical inadequacies, such as their inability to explain how children outgrow this subservient role over time.²² If a parent has a right to dictate their child's healthcare simply by virtue of being their parent, it is unclear when, why, or how they lose this right.

The most plausible and compelling reason to recognize and respect parental authority independently of children's best interests is its role in preserving family structure and stability.

²¹ Howe, "Do Parents Have Fundamental Rights?"

²² Millum, "How Do We Acquire Parental Rights?"

For the family unit to survive and flourish, some decisions must be made on behalf of the collective group. Not every decision can or will be in the individual best interest of every constituent member. Such decisions may still be morally permissible because they preserve the family's cohesion. For example, a cross-country move may be in the best interest of a parent whose job is relocating, but contrary to the best interests of their children, whose lives will be uprooted. Exercising parental authority to facilitate this move is morally permissible when considered in terms of its effect on the family unit, although doing so compromises the best interests of each individual child. One limitation of family-oriented parental authority is that because the family unit itself isn't actually an autonomous entity, judgments about what is or isn't best for the family must inevitably be made by one or two representative members. Conflict about those judgments cannot be resolved in holistic terms. For example, a disagreement between parents about whether or not moving across the country is in the family's best interest will inevitably be reduced to arguments about the combined individual interests of constituent family members. The scope of this account is also limited to justifying decisions made on behalf of the family as a whole. It does not suggest that parents may undermine their children's best interests for the purpose of advancing their own. Family interests are typically only impacted by intense or long-term medical treatments, and are therefore not relevant to all pediatric medical decision-making.²³ For example, while it may be in the best interest of a child with cancer to receive treatment at a world-class research institution, a family-centered account of parental authority would permit his parents to choose a smaller, local hospital if the distance would require some family members to relocate for several months. However, if the child's parents were Christian Scientists, family-centered parental authority could and would not justify their

²³ Baines, "Family Interests and Medical Decisions"

decision to forego any sort of medical treatment because such a choice would be based on their personal belief system rather than the benefit of the family unit. Additionally, while children may learn valuable lessons from occasionally sacrificing or compromising their own desires for the good of the family group, asking them to sacrifice or compromise their physical health and/or bodily autonomy sets a dangerous precedent. Being a good family member does not require children to subvert all of their individual interests, especially in medical decision-making where the stakes are far higher than inconvenience or displeasure.

Parents as Decision-Makers in Pediatric Medicine

While family-oriented parental authority may legitimize some decisions that are contrary to the best interests of a child, it is unclear to what extent this can be true of healthcare-related decisions. Medical treatment is decidedly different from other forms of child-rearing: it does not merely shape a child's environment, but his physical body. Depending on the kind of intervention and the developmental stage of the child at the time it is administered, the downstream effects of some medical decisions may be profound and irreversible. Furthermore, a child's medical treatment is much more consequential for the child-patient than it is for her siblings. To use an example from the previous section, the quality of care a child with cancer receives could quite literally be the difference between her life and death, and she too would experience any and all negative effects of having her family split up so that she could receive treatment at a more specialized hospital further away from home.

Even the existence of parent-oriented parental authority could not justify medical decisions in the same way as other choices a parent might make. The asymmetry of the parentchild relationship is such that parents will not be harmed by violations of their authority to nearly the same degree that children may be harmed by violations of their bodily autonomy.

Parent-oriented parental rights treat parenthood as a major component of a fulfilling life. Children's bodily autonomy, on the other hand, is not a mere component of their lives; it is central. For this reason, prioritizing parental preferences over child preferences in pediatric medical decision-making would constitute a far greater violation to children than prioritizing child preferences would to parents.

Parents' decisions about their child's medical treatment may be influenced by a number of things that would not factor into a decision made by the child-patient himself. The interests of the child's siblings are a good example of this. Parents have an equal moral obligation to each of their children, and asking them to make a decision for one child's healthcare that would undermine the interests of their other children would put them in an impossible situation. Pediatric patients have the greatest stake in their own health and medical care, and are therefore more likely to make decisions that are truly in their own best interests. Parents' emotions may play a significant role in their reasoning and choices for their children's medical treatment. A parent may be unwilling to let their child undergo a surgical procedure for fear of complications even when such complications are rare and a successful surgery would greatly improve the child's quality of life. Religion is another powerful force in parental medical decision-making. Christian Scientists, for example, have been known to let their children die of easily treatable conditions rather than seek out medical care, because they fear condemning their children to eternity in hell by allowing them to receive treatment for what they believe to be a spiritual affliction. The quality of parents' decisions may also be diminished if they harbor any prejudices toward certain kinds of treatment. For example, parents of a child with bipolar disorder may refuse to fill a prescription for a mood stabilizer because of their philosophies around psychotropic medication, even though such medication would be highly effective in restoring

their child's safety and stability. In situations like these, it is unclear why parental preferences should be given priority over patient preferences. A child faced with dying a slow death of untreated diabetes or failing out of school due to uncontrolled mania is likely better able to appreciate the cost of forgoing treatment.

If parents are uniquely qualified to make medical decisions for their children because of how familiar they are with every aspect of their lives, and if physicians are uniquely qualified to make medical decisions for pediatric patients due to their clinical experience and scientific expertise, it stands to reason that parents who are physicians would be the most qualified group of all to make medical decisions for children. However, the American Medical Association Code of Ethics explicitly forbids physician-parents from treating their own children and other immediate family members, thereby recognizing the ethical relevance and practical consequences of the emotional investment associated with parenthood. If a physician with both technical expertise and personal insight into the child's best interests is considered unqualified to make clinical decisions, then a parent without medical knowledge would be even less likely to make sound decisions in highly emotional circumstances.

CHAPTER II

EVALUATING DECISIONAL CAPACITY

Within the large body of literature on pediatric medical decision making, minors are seldom treated as authorities on their own best interests. This is because adults consider them to lack decisional capacity. The specific thresholds of age and “maturity” required from children to justify their autonomy vary widely among medical, legal, and political spheres, as well as among matters within each of those areas. Other inconsistencies are seen in the strictness of standards used to evaluate the decisional capacity of minors in comparison to the more lenient standards used to evaluate adults. When the same measures are applied to both adults and children, the difference in decisional capacity between the two groups is remarkably smaller.

It goes without saying that children have the potential to make bad decisions about their healthcare. However, adults can and do make bad decisions of their own. In recent years a backlash against “vending machine medicine” has prompted calls to check patient autonomy with the professional expertise of doctors. The degree of autonomy patients should have can and has been discussed elsewhere; the argument presented here suggests that whatever the proper amount of autonomy may be, it should be recognized in patients of all ages.

In this chapter, I review the usual reasons for denying that children are capable of making their own decisions and argue that these arguments are far too weak to support a categorical denial of decision-making authority to minors. The first part of this chapter discusses the related concepts of competence and capacity and their role in determinations of the decisional capacities of both children and adults. The second part examines the ability of children and adults to provide informed consent in terms of their capacities for understanding relevant information and

appreciating the consequences of their choices. The third part contrasts the decisional capacity for reasoning with rationality. The fourth and final part of this chapter describes ways in which information about human brain development has informed judgments about decisional capacity, providing several examples used in law.

Competence and Capacity

In the context of adult medical decision-making, competence and capacity are two closely-related terms. Competence is a legal designation, while decisional capacity is determined via clinical evaluation. Adults demonstrate decisional capacity when they are able to give informed consent, which requires that they 1) understand the relevant information, 2) articulate a choice, 3) justify their decision with internally consistent reasoning, and 4) understand the long-term consequences of that choice.²⁴ Adults are considered competent until proven otherwise – that is, in order to lose decision-making authority in their own medical treatment, they must demonstrably fail to meet the above criteria, which would likely result in their being declared incompetent.

The decisional capacity of children is evaluated by different means. One such example is the standard of “Gillick competence,” which was established in the United Kingdom and is now used in other Commonwealth countries, including Australia. It was established as a result of a 1986 court case in which a mother objected to a Department of Health policy that would allow doctors to administer contraceptives to children younger than 16. The court ruled that children could be considered competent to consent to medical treatment upon demonstrating “sufficient maturity and intelligence” to understand the nature and consequences of that treatment. A determination of Gillick competence is made in the context of a particular decision; children

²⁴ Searight and Hubbard, “Evaluating Patient Capacity”

must meet higher thresholds of maturity and intelligence to consent to more serious treatments. The consent of a Gillick competent child is sufficient but not necessary for doctors to legally proceed with treatment; one or both of that child's parents may provide consent in their place. In other words, a child's maturity and intelligence may validate their consent to a particular intervention, but not their refusal. This means that Gillick competence is not a measure of competence at all; decisional capacity exists before an actual decision is made, and therefore is not determined by the particulars of that decision. Children are not particularly empowered by this ruling, because it only gives them permission to side with the judgment of physicians over that of their parents.

By determining pediatric decisional capacity on the basis of a child's qualities (like maturity and intelligence) rather than abilities (like comprehension, communication, reasoning, etc.), we subject them to a standard that is both more demanding and more arbitrary than that applied to adults. Maturity is a nebulous and problematic concept, both because its perception depends on the subjective viewpoint of others, and because the overall maturity of a child is less important than the maturity demonstrated by a given decision. This demonstration may as well be described in the terms of understanding and reasoning used for adults, which, as we saw earlier, is determined based on specific capacities. Assessed honestly and accurately, decisional capacity should represent a state where children actually begin to make their own medical decisions, not a point at which it becomes morally impermissible for others to make decisions on their behalf. Because decisions about serious medical decisions demand more cognitive power than those about minor decisions, it is reasonable to evaluate decisional capacity on a case-specific basis.

Part of the reason children have been held to a more stringent standard is because they are considered by default to lack decisional capacity. As a result, giving them decision-making power necessarily entails removing that power from their parents. However, as discussed in the previous chapter, parents do not have a strong enough claim right to decision-making power to justify depriving children of the opportunity to make their own medical decisions. If children previously considered incompetent are determined to have decisional capacity when evaluated with the same four criteria applied to adults, this simply means that there are children who are being denied the opportunity to exercise their decision-making abilities to their full potential. Granting pediatric patients' autonomy does not need to be an exception to a rule.

Applying the criteria for adult decisional capacity to children would mean that any child able to 1) understand the relevant information, 2) articulate a choice, 3) justify their decision with internally consistent reasoning, and 4) understand the long-term consequences of that choice should be allowed to make a decision independently, even one to which their parents object. First and foremost, decisional autonomy requires the capacity to articulate a choice. Language skills are acquired gradually in early childhood, so the ability to articulate a choice is what naturally limits the decisional capacity of children. Additionally, parent-child disagreement is only possible if a child articulates a preference different from that of their parents. Methods for evaluating the capacity to articulate a choice will not be discussed in further detail. The remaining three criteria – the capacities of children to understand information, provide reasoning for their decisions, and foresee the long-term consequences of those decisions -- will be examined below in the remaining sections of this chapter. I will argue that children's abilities are far more on par with those of adults than we may think them to be, and that our beliefs to the contrary stem from social norms.

Informed Consent

A patient gives “informed consent” when agreeing to undergo a treatment or procedure after having considered all relevant facts about the medical condition and intervention in question and weighing possible alternatives. Providers are legally and ethically bound to obtain informed consent from their patients before proceeding with treatment. This standard is intended to safeguard patient autonomy by eliminating any ambiguity as to whether or not a patient’s consent was given freely in light of salient information. By its very definition, meaningful and legally valid informed consent can only be given by individuals with the capacities to both understand all relevant information and appreciate their conditions and the likely outcomes of every possible treatment.

It is especially noteworthy that patients are evaluated on their *capacity* to understand the new information doctors provide to them, rather than on the amount of background knowledge they already possess. Capacity for understanding is something that can be actively demonstrated, while existing knowledge is something that would be passively quantified. The proportion of the population with the capacity to understand information about a new diagnosis is far greater than the proportion of individuals who are likely to know that information already. Additionally, a patient need only understand *relevant* information – educational background, language barriers, and cognitive ability may preclude patients from immediately grasping information at the same level of complexity as do their doctors. Such a level of understanding is not required in order to meet the standard of informed consent, which functions primarily to prevent misunderstandings that may alter a patient’s ultimate decision.

Capacity to understand information is gauged in a variety of ways: patients may be asked to describe the facts of the scenario as they understand them, summarize and reflect information

they have recently been given, and so on.²⁵ All of these strategies require that understanding be actively demonstrated. Such a demonstration is only possible if doctors provide their patients with the information of which they need to demonstrate understanding.

Because children are, by default, treated as lacking decisional capacity, their healthcare providers may not think it necessary to furnish the important details of their medical condition. As a result, the presumptive inability of children to understand important information is never challenged, so many children who *do* possess a capacity for understanding information may never be identified. Those children are then denied an opportunity to exercise their patient autonomy, not due to any deficiencies in their decisional capacity, but because of their age. Even one such incident deprives a child of an opportunity to *practice* achieving and successfully demonstrating their understanding of health information.

Age is a poor approximation of decisional capacity for several reasons. First, existing notions of what ages correspond to what capacities are skewed. They significantly underestimate the abilities of preadolescent children and rarely distinguish among

them, even though the capacities of a seven- and eleven-year-old are quite different. A focus on age overlooks another very important factor in the development of decisional capacity: past healthcare experience.²⁶ A child with a chronic or severe illness that requires extensive, long-term treatment will be far more able to understand medical information than a child visiting a doctor for the first time. Finally, age-based defaults also overlook exceptions on the other end of the spectrum: adults who are presumed to possess decisional capacity, but do not.

²⁵ Searight and Hubbard, "Evaluating Patient Capacity"

²⁶ Hoffmaster, "The Rationality and Morality of Dying Children"

In general, children are far more skilled at gathering and understanding information about their health than is often suggested. In her widely-cited book, *The Private Worlds of Dying Children*, anthropologist Myra Bluebond-Langner shares the stories of terminally ill children she interacted with on a pediatric leukemia ward.²⁷ Over the course of their clinic visits and hospital stays, even very young patients were able to discern the hierarchy among staff members and infer their conditions based on how often their blood was drawn and which medications they were prescribed. Every one of the children had realized they were dying before their doctors or parents broached the topic.²⁸ They were excluded from conversations about their prognoses, but still managed to collect a variety of evidence: the worsening conditions and eventual disappearances of other hospitalized children; details gathered by eavesdropping on nurses' conversations; the absence of any planning for birthdays, holidays or vacations; the special opportunities and gifts they received from charitable organizations; the fact that unlike their siblings, they were not expected to attend school or complete chores; and so on. Many of these children even went to the effort of concealing their insight into their conditions from their parents and healthcare providers – one boy explained that he knew his mother wouldn't be able to handle a conversation about his death, while another expressed fears that if he let on to doctors that he knew he was dying, they would give up trying to cure him. All of the children Bluebond-Langner interacted with were between the ages of 3-9, far younger than the age at which doctors would even begin to consider involving them in treatment decisions.

²⁷ Bluebond-Langner, "The Private Worlds of Dying Children"

²⁸ Hoffmaster, "The Rationality and Morality of Dying Children"

Reasoning and Rationality

To demonstrate a capacity for reasoning, a patient must be able to explain the thought process by which they came to favor one alternative over the other. Understanding relevant information is essential to informed consent, but so is the ability to apply that information in a meaningful way. Such reasoning is not evaluated in terms of how satisfying others find it, but in terms of its internal consistency. This requires that a person not hold two mutually exclusive beliefs, that they correctly understand causal relationships between treatments and health outcomes, and that their decisions reflect consistent values – in other words, that they don't change their mind frequently.

Reasoning is similar to, but different from, rationality. Whereas reasoning is a capacity, rationality is a quality – one with serious shortcomings as a predictor of decision-making ability, given that no one is rational at all times. As much as doctors may wish otherwise, rationality is not an essential feature of medical decision-making.²⁹ Adults frequently make irrational decisions that are seemingly contrary to their best interests. They are permitted to do so because their autonomy is considered worth respecting, even at the expense of a “good” choice. Minors are treated quite differently. If they act in a way that contradicts their best interests in a particular case, that action is considered to be evidence of their incompetence.

The notion that the irrational decisions of children demonstrate a lack of decisional capacity while the irrational decisions of adults do not is nonsensical. No adult acts rationally without exception.³⁰ Therefore, no child can be expected to develop into someone who acts rationally without exception. We cannot withhold decisional authority from children based on

²⁹ Djubegovic, “Rational Decision Making in Medicine”

³⁰ Vos, Shermer, and Bolt, “Recent Insights into Decision-Making”

how “rational” we deem their choices to be. If the idea of allowing children to make “bad” or irrational decisions that undermine their best interests seems outrageous, it is only because we have been spoiled by having the ability to prevent them from doing so. It is unpleasant to watch any loved one make choices that harm them, to say the least. While we may wish to step in and make better decisions on their behalf, we must begrudgingly acknowledge that it is not our place to do so. This is true of children as well. The only reason it may seem like we have a right to intervene is because this idea is politically, legally, and socially reinforced, not because such a right actually exists.³¹

Defaults and Development

Defaults in law are an unfortunate practical necessity. Adults are considered competent by default, and only in certain circumstances where several criteria are met will their right to make their own medical decisions be revoked. Conversely, children are considered incompetent by default, and only in certain circumstances, if they meet certain criteria, are they granted the authority to make their own medical decisions. However, the respective criteria with which adults and children are evaluated are different, as discussed in the previous section. If such defaults must exist, then the line between competent and incompetent should at the very least be consistent.

Consistency, however, is nowhere to be found in laws regarding age limits. Minors between the ages of 12 and 18 may be treated like adults in different contexts. Criminal prosecution, driving, purchasing certain goods, holding certain political offices, consent, and more each involve different age cutoffs. The law does not use a consistent approach to determine the competence of children in various contexts. Organ donation is an interesting example. States

³¹ Howe, “The Dead Dogma of Parental Rights”

decided that capacity to drive also established the capacity to donate organs, even though these two types of activities are not intrinsically related. This was done because teen drivers are much more likely to die in car accidents, and donating organs is a good to society. In other words, attributions of competence were based on the interests of the community, not on the abilities of the teenagers. Minors are already permitted to receive some types of healthcare without parental consent. Some of the most notable examples include reproductive healthcare, substance abuse treatment, and mental health counseling.

In medicine, and increasingly, in law, rulings of global “incompetence” have been replaced by rulings of “capacity” in much narrower scope, because capacities are not necessarily interdependent. For example, while an elderly person might have lost the capacity to drive, he may still have the capacity to make financial decisions. Evaluating these capacities separately may be more complex, but it ensures that adults do not lose any more autonomy than “necessary” to preserve their best interests and well-being. This approach should be used to evaluate the decisional capacities of minors as well. The reason it has not been is because pediatric autonomy has been treated as less important and incompetence is the presumed default.³²

³² Coleman and Bosoff, “Legal Authority of Mature Minors”

CHAPTER III

EXPANDING PEDIATRIC PURVIEW

The previous two chapters have presented arguments for reconsidering the status quo in pediatric medical decision-making. For the most part, my strategy has been largely negative in that I have rejected arguments in favor of denying children the right to exercise autonomy in their healthcare. Here, I build upon those chapters with additional positive arguments for why we should actively change the status quo.

The first part of this chapter briefly reviews the role values play in medicine and in justifications of patient autonomy. The second part argues that the rights of children that would be more securely protected if pediatric purview in medical decision-making were expanded. The third part of this chapter describes several utilitarian benefits of increased pediatric autonomy and participation.

Values

While the importance of patient autonomy may seem self-evident today, it was not fully recognized in the medical community until the early 1970s. It was around this time that medicine underwent a significant cultural shift in response to two coinciding developments: revelations about human rights abuses in medical research and advances in medical technology. The outcome of these changes was more than just an increased emphasis on patient autonomy; an “adversarial tone” was established as well. Doctors, once accepted as benevolent authorities, came to be seen as potential threats to patient well-being.

Of all the human rights abuses in medical research in the 20th century, the Nazi medical experiments are likely the most well-known. Prisoners in concentration camps were used as

subjects in cruel, gruesome, and often pointless experiments. Similarly horrifying experiments have been conducted far more recently and closer to home. The most infamous American example is Tuskegee Syphilis Study, which was conducted over a forty-year period from 1932 to 1972 and studied the progression of untreated syphilis in African American men long after a cure (penicillin) had been discovered. Another, lesser-known study was the hepatitis study at Willowbrook State School for children with disabilities in Staten Island, New York. Children were fed chocolate milk mixed with hepatitis-infected feces. The result was the discovery of hepatitis A and hepatitis B as two distinct viruses.³³

Advancements in life-prolonging medical technology raised new questions about the definitions of life and death. Kidney dialysis was one of the earliest examples of such technology. When it was first invented in 1943, kidney dialysis involved an invasive procedure of piercing arteries and veins to extract blood, so its course was naturally limited by the availability of viable blood vessels. This changed in 1960, with the invention of a long-term dialysis treatment. The machines necessary for this treatment were extremely limited, making resource allocation a matter of life and death for patients. Scribner recognized that doctors would be unable to make these determinations on their own, because each doctor is obligated to advocate for their specific patient. This resulted in the formation of a bioethics committee, consisting of professionals from various fields, that would make the decision. Another key development was that of successful organ transplants. This created a new incentive for doctors to avoid prolonging life at all costs.³⁴ These developments prompted the realization that clinical and scientific expertise did not always translate into good medical decision-making.

³³ Lynch, "The Origins of Bioethics"

³⁴ Rothman, "Strangers At The Bedside"

It is important to highlight that patients did not fight for autonomy on the grounds that they were equally rational or qualified to make scientific decisions than doctors, but because medical decisions often require value judgments that doctors are not necessarily more qualified to make. For example, while doctors may know best how to extend life, the choice about whether to extend life at the cost of the quality of life is one in which they have no more or better information than do patients. Similarly, parents are not more qualified to make these kinds of value judgments than their children.

Rights

In both philosophy and law, children are generally considered incapable of exercising unconditional autonomy in the same way adults do, and are therefore not recognized as being morally entitled to it. However, they must possess some sort of analogous right in order to be protected from the whims of the adults around them. A variety of attempts have been made to identify and define this right.

One highly-influential formulation is Joel Feinberg's "right to an open future."³⁵ This right to as many open options as possible prevents parents from making decisions on behalf of their children that would limit their ability to exercise their right to autonomy upon reaching adulthood. Some critics of the right to an open future point out that the decisions required to maximize a child's future options may be contrary to their present interests. For example, in order to ensure that their child has the option to pursue any sport professionally, parents would need to require him or her to play every sport on a competitive level throughout the year, something that would likely be unrealistic and unenjoyable for the child. Children's futures are inevitably limited by things like the schools they attend, the activities in which they participate,

³⁵ Millum, "Child's Right to an Open Future"

and their parents' professions. Any decision made by a child's parents would therefore constitute a violation of their right to an open future, which seems unfair for obvious reasons.

Jason Chen seeks to improve upon Feinberg's argument by advocating for what he calls "the right to self-development."³⁶ While the right to self-development also requires that children have meaningful options available to them as adults, it protects their present interests as well. Whereas the right to an open future suggests that children are morally entitled to as many options as possible, the right to self-development emphasizes their ability to make meaningful choices, even though those choices will be from an inevitably limited number of options.

The way children choose to exercise their right to self-development may at times conflict with the way their parents wish to exercise their "right" to raise their child in a particular way. The right to self-determination is a liberty right, so it only requires that parents stand passively by and refrain from interfering in their children's decisions. If invoked in an attempt to resolve a parent-child disagreement, the parental right to raise one's children in a particular way would constitute a claim right to their children's obedience. If such a right were philosophically sound, it would still be "asking more" of children than children's rights to self-development ask of their parents. This difference in the magnitude of the sacrifice asked of each party is only increased in healthcare: siding with parental preferences in pediatric decision-making means that children may be forced to forgo medically recommended treatments that their parents dislike or be subjected to treatments and interventions against their will.

Benefits

For both children and adults, participation in treatment decisions is a strong predictor of treatment compliance and effectiveness. Any reason for which someone is reluctant to undergo a

³⁶ Chen, "The Right to Self-Development"

certain treatment or take a particular medication can also serve as a reason to be noncompliant or skip doses. In terms of health outcomes, a less-than-ideal treatment carried out thoroughly is likely to be more effective than an ideal treatment that is haphazardly applied. This has actually been used as justification for allowing parents to make decisions doctors consider subpar – it has been suggested that rather than insisting on what they consider the best treatment option and risk alienating a child’s parents or being fired by them altogether, doctors should defer to parents.³⁷ For this reason, children acting as the primary decision-makers in their own medical care would likely result in better health outcomes if they are fully committed to the treatment approach they choose. Additionally, they develop valuable skills and attitudes as a result of being allowed to take responsibility for their healthcare.

Inviting children to participate in medical decision-making also helps facilitate a positive therapeutic relationship between the child and the doctor. There is a significant rhetorical difference between addressing children as the most valuable source of information and asking them to supplement their parent’s reports with additional details.³⁸ Clinicians rely heavily on children to communicate their symptoms. For chronic illnesses, psychiatric and neurological disorders, and especially illnesses characterized by pain and/or fatigue, children may report significantly different symptoms or severity of symptoms than their parents would.

³⁷ Navin and Wasserman, “Amplifying Parental Permission”

³⁸ Olzewski and Goldkind, “The Default Position”

CONCLUSION

Even though infants are born completely dependent and unable to exercise autonomy, children should not be considered incompetent by default. The result of this, as discussed in Chapter 2, is that children are required to meet much higher standards of than adults to prove themselves capable of making a decision.³⁹ Children develop at their own pace, and this is especially true in the context of medical decision-making where past experiences, personality, and family dynamics influence how ready and willing they are to make decisions for themselves. A twelve-year-old with cancer who has undergone several rounds of chemotherapy and years of treatment may have the confidence and capacity to make the decisions most likely to achieve his desired outcomes. A sixteen-year-old with cancer who has just been diagnosed may not want to know the details of her condition, instead asking her parents to handle the logistics on her behalf. The wishes of both of these children are perfectly acceptable; permitting one does not necessarily invalidate the other.

Every child has a right to autonomy from birth, simply by virtue of having a body. While this right remains unchanging, children's ability to exercise it develops over time. They must develop the abilities to communicate with the world around them, to understand themselves as separate from their environment, to question and reflect on what they learn from others, to introspect, to form and identify goals and desires – none of which are quantifiable for the purpose of evaluating decisional capacity, but all of which are relevant.

In their early years, children are too young to desire or even understand decisional autonomy. Parents – or another type of custodial figure – must stand in as medical decision-

³⁹ Katz and Webb, "Informed Consent in Pediatric Practice"

makers, not because it is their right or privilege, but because decisions cannot be deferred without consequence. This reality is more or less recognized as fact. At the other end of the spectrum are children approximately 14 and older, who not only understand and desire decisional autonomy, but often demand it. Some health policies have recognized the relatively arbitrary nature of the age of majority, and allow adolescents to independently consent to a variety of procedures including those related to treatment for substance abuse and sexual healthcare.

Many children, however, fall into a developmental middle ground that has not received justice in medical decision-making. They have developed some decisional capacities, but not all.⁴⁰ They are increasingly aware of their identities and values, but may not know what decisions are most congruent with those. Treating them the same way we do very young children is just as inappropriate as treating them like adolescents. Children's right to autonomy is constant, so they should be allowed to exercise it to the fullest extent possible given their present capacities.⁴² The job of a parent or guardian is simply to make up the difference; they may only override children's decisions on the basis of the capacities they lack. Because children develop the capacity for preferences before they are fully capable of foreseeing hypothetical outcomes and reasoning about cause and effect, parents may override their children's decisions by substituting their hypothetical and causal reasoning but must respect their preferences. For example, if a six-year-old child refuses to receive a vaccine because shots are painful, his parents may override his refusal because their capacity for reasoning and foresight allows them to recognize that the prick of a needle is far less painful than the illness the vaccination prevents, so consenting to receive the shot is most consistent with his preference. However, say another six-year-old child refuses

⁴⁰ Grootens-Wiegers, "Medical Decision-Making: Neuroscientific Aspects" ⁴²⁴²
Miller, "Beyond the Concept of Ability"

to take the medication prescribed to him for ADHD, because it makes him feel “not like himself.” His decision is valid and should be respected, because ceasing the medication is the best way to accomplish his desired outcome. His parents could not justifiably coerce him to take the medication on the grounds that it improves his behavior at school, because in doing so, they would be substituting their own preferences – a capacity for which their son has clearly already developed.

Understood this way, the role of parents in pediatric medical decision-making in effect only allows positive overrides, not negative ones. That is, while parents can provide proxy consent for a treatment their child would refuse in some – but certainly not all – cases, they cannot prevent their child from receiving a treatment. This is not because positive and negative overrides are ontologically distinct, but because children independently consenting to a treatment is evidence of the fact that they prefer to receive it, something parents cannot overrule.

The institutional implementation of this principle would be complicated by legal, clinical, and social practicalities that should be addressed in future discussions. However, this expansion of pediatric decisional autonomy is essential to public health, child welfare, and at the very least, the internal consistency of the formal discipline of bioethics.

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