Too Close to the Knives: Children's Rights, Parental Authority, and Best Interests in the Context of Elective Pediatric Surgeries

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Dedication

I would like to dedicate this work to my mother, who taught me that learning is intrinsically valuable.

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I would like to thank David D. DeGrazia for his invaluable comments, guidance, and suggestions throughout the process of writing this thesis paper.

Abstract of Thesis

Too Close to the Knives: Children's Rights, Parental Authority, and Best Interests in the Context of Elective Pediatric Surgeries

This thesis paper defends a novel conception of the child's best interest in regard to elective pediatric surgeries (EPS). First, children's capacity for decision-making is examined, and the best decision-making model for EPS is identified as the Best Interest Standard. What follows is a discussion of the interests of children in EPS, the correlation of fundamental interests to rights, and guidelines for weighing children's competing interests. Next, the role of families is considered, especially the rights and duties of parents. Finally, a reinterpretation of the Best Interest Standard is proposed, identifying as paramount a child's ability to make elective medical decisions for herself when she reaches maturity.

Table of Contents

Section 1: Introduction

A. Cases

1. Walter and Skyler are overjoyed to welcome their second child, Holly. While she is the picture of robust infant health, the bones in Holly’s lower legs did not develop at the same rate as the rest of her body in utero. As a result, her legs will never grow in a way that will afford her typical mobility. While still in the hospital post-delivery, Skyler’s OB/GYN advises the couple to consider which surgical option they will pursue: an above-the-knee amputation to allow Holly to wear prostheses, or limb lengthening procedures to lengthen the bones of her lower legs through a fracture and artificial regeneration process.

2. Jesse is a healthy, yet unhappy, ten year-old boy who was born with a cleft lip and palate. These clefts made feeding difficult as an infant, and his parents authorized two surgeries to repair the abnormalities. The initial clefts, as well as the surgeries, left Jesse with an atypical appearance: his nose and upper lip are misshapen and he bears a large surgical scar. Jesse struggles with fitting in among his peers and is frequently teased at school about his appearance. As a result, he is socially withdrawn, acts out, and performs poorly in his classes. Jesse has been under the care of a psychologist, Dr. Goodman, since he was eight years old. Despite years of care from Dr. Goodman, Jesse’s psychological health continues to deteriorate. Jesse admits to Dr. Goodman that he engages in self-harm as a way of coping with the stress caused by his appearance. Jesse’s parents are considering additional surgery for Jesse that would cosmetically improve his appearance by reforming his nose, upper lip, and minimizing his surgical scar.

3. Hank and Marie are in the hospital following the delivery of their first child, who is born at term and has a strong APGAR score. However, the baby has ambiguous genitalia, making it difficult to determine its sex. Testing indicates that there are no problems in the urinary tract or other areas that would require medical intervention. Nonetheless, their pediatrician, Dr. Ehrmantraut, tells the new parents that the baby's ambiguous genitalia represent a serious condition that will have a profound effect on the child's ability to form a gender identity, potentially leading to negative effects on the child's psychological well-being. Based on the characteristics of the child's genitalia, Dr. Ehrmantraut recommends Hank and Marie raise their child as a girl. To be effective in assigning a female gender to the child, Dr. Ehrmantraut instructs the parents to authorize a surgery to construct a functional vagina and follow up with hormone therapy when the child reaches adolescence.

4. Flynn is sixteen months old and was born deaf. His parents are hearing and would like their son to share this sense to maximize his educational, social, and professional opportunities. They have been in consultation with an audiologist about the appropriateness of surgery for a cochlear implant. The audiologist advises the parents to schedule the surgery before Flynn is two years old to maximize development of his language faculties.

B. Opening

This thesis paper explores the ethics of parental consent for elective surgeries performed on minor children. Elective surgeries are those that do not serve a medically preventive purpose or treat an existing illness or injury. I will argue that clinical practices that permit parents[1] to consent to elective surgeries on behalf of their minor children frequently do so at the expense of the children's rights to make self-determined choices as adults.

Before conducting an ethical analysis, I will begin by delineating the medical context for this paper. First, I will identify the types of surgeries under consideration before exploring the cognitive and developmental factors that prevent most children from acting as their own primary healthcare decision-makers. This will lead to an overview of several models for medical decision-making, followed by a justification for adopting the Best Interest Standard as the most appropriate guidance for parents.

After defining the medical context, I will consider the ethics associated with the authorization of elective surgeries on children. First, I will articulate four categories of interests held by children: bodily, psychosocial, cognitive, and autonomy interests, each of which features a threshold representing a minimal acceptable level of care. I will argue that these thresholds correlate to rights held by children to their fundamental interests. Second, I will explore appeals to children's interests when parents pursue elective pediatric surgeries on behalf of their children, proposing guidelines for how children's competing interests should be weighed in the decision-making process. Third, I will discuss the rights and duties of parents, ultimately adopting a stewardship model of parental authority as the most successful. Finally, I will propose a new interpretation of

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[1] In the context of this discussion, I consider non-parental legal guardians to be analogous to parents, as they exercise similar authority to direct the healthcare of minor children under their custody. I also assume that legal guardians will share an intimate relationship with the children they care for. For a thorough discussion of what characteristics define parenthood, see Austin 2007.

the child’s best interest, which emphasizes a child’s future choices alongside her immediate welfare. I will conclude by considering the policy implications of this conception and recommending topics for further research.

Section 2: The Medical Context

This section will define the context for the subsequent ethical evaluation by defining the types of surgeries under discussion and exploring children’s relevant capacities for medical decision-making.

A. Surgical Scope

The scope of this analysis will be limited to elective surgeries performed on children (elective pediatric surgeries, or EPS). While I do not propose an exact age group, I will broadly consider pre-adolescent children for this analysis. I presume that these children will become legally and cognitively competent to act as their own healthcare decision-makers in the future. This analysis may not be applicable to terminally ill infants, children with severe developmental disabilities, or other children who we cannot reasonably believe will grow to cognitive and legal maturity.

In this context, elective refers to surgical procedures that 1) are not empirically likely to make significant contributions to the prevention of illness or disease (either mental or physical), and 2) are not medically indicated to treat an existing illness or injury. Elective surgeries are optional in nature, whereas preventive and therapeutic surgeries are likely to make contributions to the patient’s health by preventing an illness or treating an existing illness or injury.[2] The four cases at the opening of this paper illustrate some of the kinds of surgeries under discussion. Many of these surgeries are intended to correct disabilities, developmental abnormalities, or other causes of atypical appearance or ability. Such interventions include limb lengthening (most often performed on children with forms of dwarfism), gender reassignment of infants, and operations to address a range of craniofacial abnormalities. EPS also includes surgeries to improve unwanted aspects of a child's appearance, such as the removal of birthmarks or otoplasty (commonly called ear pinning). This analysis is also directed toward medically and socially controversial procedures such as the routine or religious[3] circumcision of infant males in developed nations, the medical utility of which is disputable (Malone and Steinbrecher 2007).

When discussing EPS, one should not consider the surgeries themselves to be ethically suspect: it would be permissible for any adult to pursue these procedures of her own free will. Once a child has reached the age of majority, I presume that she will be

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[2] The aim of this thesis paper is not to undermine a parent's duty to promote the comprehensive health of her child by seeking clinically appropriate surgical interventions. Parents, in consultation with health care practitioners, should be afforded significant leeway in determining what interventions will best respond to the unique preventive and therapeutic health needs of the child in question. In this spirit, every possible consideration should be given to ways that a surgery could promote the physical health of the child when determining if that surgery is preventive, therapeutic, or elective.

[3] Some argue that circumcision performed for religious reasons should be permissible, because it results in no net harm to the patient and falls within the realm of reasonable actions taken by parents to rear children as they see fit. First, the claim that infant circumcision causes no net harm is dubious: it undeniably causes pain, however temporary. It also permanently alters the child's body at a time when he cannot provide even cursory assent to the procedure. Finally, the foreskin contains the highest concentration of nerve endings in the penis, and its removal leads to a reduced capacity for sexual pleasure. In contrast, there is no benefit to the patient by being circumcised in infancy. The claim that membership in a religious community counts as a benefit to the child is debatable, as an infant cannot enjoy many benefits of community membership. See van Howe 2012 and Bronselaer et al. 2013.

within her authority to pursue these surgeries on her own behalf. The ethical questions explored in this paper do not concern the appropriateness of utilizing medicine to shape appearance or ability. Instead, I am concerned with utilizing medicine to permanently alter the appearance or ability of a patient who is unable to fully participate in the process of choosing that surgery, and who we have reason to believe will become competent to participate in that process at a later date.

Many forms of EPS are justified as being socially normalizing: their primary purpose is not to respond to present health needs, but to aid in psychosocial development. The normalization of children through surgery seems to call upon us to consider the values that such surgeries reflect (Little 1996, Lindemann 2006). However, focusing on the values themselves is a misdirected cause. Regardless of which values are at play, what has the potential to be ethically problematic is that the values reflected by EPS may not belong to the child who will be directly impacted by the surgery. From this perspective, the primary focus is the fundamental importance of ensuring that the person who will bear the consequences of a surgery is having her values considered when the surgery is selected. To do this, we must promote the capacity of persons to make self-determined choices about how – or if – to express their values through medicine.

B. Children's Capacity for Medical Decision-Making

Children are presumptively regarded as incompetent to make their own medical decisions. This default presumption reflects that competence is, in part, a legal issue. Each jurisdiction has its own rules concerning the age at which persons are legally permitted to make their own medical decisions; in the United States, this age is eighteen.[4] Until their children are legally emancipated, parents have the authority to provide consent for medical interventions on behalf of their children. These legal provisions reflect a child's developing capacity for medical decision-making.

Allen Buchanan and Dan Brock have helpfully identified three key characteristics for competence to make medical decisions: capacity for understanding and communication; capacity for reasoning and deliberation; and development of a set of values and conception of the good (Buchanan and Brock 1989). Capacity for understanding and communication means that a person must be able to participate in the process of becoming informed about a treatment and be capable of expressing a preference about that treatment. This is not merely a perfunctory process, but requires the ability to consider possible alternatives and to integrate hypothetical outcomes into a decision-making process. The capacity for reasoning and deliberation requires at least some capability for probabilistic reasoning and the ability to draw inferences about the consequences of a given choice. Finally, the development of a set of values and conception of the good requires a relatively consistent value set that guides a person in granting weight to desired paths or outcomes.

Competence is context-specific and is relative to the kind of decision that must be made. To determine that a person is competent to make a decision about EPS means that she possesses the relevant capabilities for understanding, communication, and reasoning about the risks and benefits of the procedure, as well as a relatively stable set of goals and

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[4] There are notable exceptions to this guideline, including those established by legislatures, state courts, and the Supreme Court that permit access to health services without parental consent in emergency situations and for reproductive health services.

values to guide her decision. Many children fall beneath this relevant, context-specific threshold. However, it is important to note that incompetence to make one medical decision does not demonstrate incompetence to make *any* medical decision. For instance, a four year-old may possess the competence to choose which ear to have his temperature taken in, but he would not have the competence to choose among a variety of antibiotics to treat an ear infection.

A child's development of the characteristics necessary to meet the threshold level of competence for medical decision-making generally parallels her cognitive development; this capacity will normally increase as the child ages. Research has shown that children typically develop the relevant cognitive capacities for medical decision-making around adolescence. Sometime after puberty (typically between the ages of ten and fourteen for girls and between twelve and sixteen for boys), children become capable of abstract thinking (Piaget 2010) and integrating past experiences into making decisions about the future (Baird 2008). Both capacities are necessary for the exercise of probabilistic reasoning, which is central to medical decision-making.

To be considered competent, a patient must exhibit not only the cognitive skills necessary to understand the potential risks and benefits of a surgical intervention, but also the capacity to appreciate this information. That is, the patient must understand what the procedure will mean for her sense of self and ability to pursue goals that are consistent with her values and life plans. Many children show an advanced capacity for this kind of appreciation; it is especially evident in medically complicated children and those who have faced substantial adversity (Alderson 2006). However, even in these children, there are concerns about their capacity to make medical decisions that cohere with a developed vision of the good life. Since there is no one authoritative vision of the good life, persons need to be able to contemplate and choose among options that reflect their distinctive goals and values. This has less to do with cognitive capacity than it does with a child's development of her own unique character and life plans. For many people, pursuing their conception of the good life means stepping away from parents, families, and peer systems to make choices that are independent of these forces. For others, the good life is closely tied to their intimates, and they involve others in making plans that promote shared goals and values. Children do not develop a conception of the good life on a defined timeline that correlates to their age; indeed, many adults struggle to identify the goals or values that characterize their conception of the good life.

Because EPS precludes significant alternatives, it is especially important for patients to have a relatively stable set of values that guides their decision-making. EPS can have a profound impact a person's sense of self, their relationships with others, and their ability to pursue certain life goals. Some people take pride in overcoming adversity, while others believe it is preferable to minimize adversity and maximize other interests. These are value judgments that reflect individual preferences, which underscores the importance of a patient's ability to appreciate how electing to have surgery (or opting not to have surgery) will advance <u>their</u> life goals and promote the values those goals reflect. Acquiring such an appreciation is generally a personal process grounded in self-reflection informed by an awareness of one's place within her peer groups and communities. Children are in a difficult position to exercise this kind of reflection; even those who exhibit exceptional cognitive capacities, emotional maturity, and a defined sense of self can be susceptible to influence from others, especially authority figures and peers (Baird 2008; Ross 1998, 60).

Section 3: Models for Medical Decision-Making

In light of children's presumptive incompetence to make medical decisions on their own behalf, several models have been developed to guide clinical decision-making for pediatric patients. I will discuss three such models here: Children's Liberation, Shared Decision-Making, and the Best Interest Standard. The first two attempt to address some of the apparent conflicts present in the parent-child relationship, while the third holds that the intention to maximize the child's interests should determine the best course of action.

A. Liberation Front

The foundational claim of Children's Liberation is that that the social institutions of childhood are inherently unjust to children. From this claim, liberationists argue that children should have access to the same rights that adults enjoy (Holt 1980). On the view of the liberationist, children of any age should be free to choose any medical intervention they like (along with any home environment, any job, and so on).

Despite the obvious deficiencies of this view, I would like to briefly consider it to outline its contributions to the present discussion – specifically, how parental authority may be wielded in ethically problematic ways. It is apparent that granting children full authority to guide all aspects of their lives is radical and unwise. But however skeptically one may view Children's Liberation, the movement raises some important questions about the moral dimensions of adults' authority over children. Children's Liberation argues that parental authority can be exercised in ways that undermine a child's fundamental right to make self-determined choices, which is disrespectful of the child's full moral status (Palmeri 1980). However, Children's Liberation makes a fatal flaw in assuming that because children have the same moral status as adults, they should have the same rights as adults. Such a view ignores that most children are lacking in the characteristics required to exercise decision-making in many contexts.

It would be problematic to grant children the same set of decision-making rights as adults because they do not have the same interests as adults. In the context of EPS, a child has an interest in knowing that available alternatives have been explored; in understanding the possible outcomes of such a surgery; and in appreciating how the decision to have surgery will affect her ability to pursue goals and life plans consistent with her values. A parent can supplement some of these capacities – she can research likely outcomes of a procedure and seek guidance on optimal alternatives – but no adult can act as a spokesperson for the values, goals, or life plans that a child has yet to adopt. The adoption of such goals and values is consistent with adults and older adolescents, but not typically found in young children.[5]

A child's short-term autonomy or liberty can be justifiably undermined in the name of promoting her rights and interests over the course of her lifetime (Feinberg 1980). There is a legitimate claim that a child's lifetime interests are best promoted by a

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[5] Howard Cohen proposes that child agents be deployed to supplement children's developing cognitive capacities to assist children in the exercise of the full set of rights enjoyed by adults. Child agents would be very unlike parents: they would not be responsible for protecting children or keeping them from making mistakes; rather, they would be there to supplement the cognitive abilities of the child when making decisions. Cohen's proposal is nonetheless subject to many the same concerns I have about a parent's capacity to complement the cognitive skills of a child in the decision-making process, which are outlined in the body of this paper. See Cohen 1980.

protected period in which to develop her capacities for decision-making (Ross 1998). On this widely accepted view, children should not be given the authority to make their own decisions about important matters such as medical interventions. Instead, adults should work to promote children's development of autonomy by including children in decision-making processes in age-appropriate ways. It consequently seems plausible that we can discard the notion of liberation and instead seek to include children in the decision making process in an effort to respect their developing capacities for self-determination.

B. Shared Decision-Making

Shared Decision-Making holds that children's presumptive incapacity to make their own medical decisions is not sufficient to deny children a voice in decision-making on matters that impact them. Many parents believe that as a child's capacities grow, she should be included in the process of medical decision-making in age-appropriate ways. In the context of EPS, Shared Decision-Making calls upon clinicians and families to give children as much information as they can understand about the purpose of the surgery, its risks and benefits, and likely outcomes (Alderson 2006). In this practice, there is ideally no one person who holds ultimate authority to make a decision about whether to pursue a surgery; instead, choices are made by consensus among children (patients), parents, and family, under the guidance of practitioners.

Shared Decision-Making recognizes that even a young child has the capacities to participate in the decision-making process in age-appropriate ways. Shared Decision-Making is also grounded in the notion that it is morally important that the patient who will undergo a procedure understand the medical details of that procedure to the best of her ability. Despite these positive characteristics, Shared Decision-Making has significant flaws that make it potentially problematic in practice. First, this model ignores the power imbalance that is at the center of parent-child relationship. This skewed power dynamic raises the very real possibility that children will not meaningfully participate in the decision-making process, but instead will parrot what those in authority would wish them to do.[6] As a result, Shared Decision-Making may create the illusion that children are real decision-making partners without acknowledging the ways that children are susceptible to pressure from authority figures.

Shared Decision-Making also presumes that a harmonious choice will be made in unison, neglecting to provide adequate guidance in instances when children and parents will come to different conclusions about the necessity of a particular intervention. In these cases, it is parents who have the ultimate legal authority to determine the best course of action on behalf of their children. This raises direct concerns about parents utilizing their authority to authorize a procedure in spite of the wishes of the child, who will be the person directly impacted by that procedure.

Finally, many children are so young at the time EPS is performed that they lack the cognitive skills to participate in the decision-making process in a way that is meaningful. Many of these surgeries are performed on infants and toddlers – children who are in the earliest stage of development and cannot provide any assent to these procedures. While Shared Decision-Making may become attractive when dealing with older patients, it does nothing to protect the interests of the youngest children, whose lack of understanding and communication capacities make them the most vulnerable.

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[6] A child who endorses those actions favored by authority figures may do so either consciously or unconsciously.

C. The Best Interest Standard

The Best Interest Standard (BIS) acknowledges both children's incomplete capacity for decision making and the importance of selecting interventions that will best promote the totality of a child's interests. While there are several definitions of the standard, each calls upon a proxy decision maker to authorize medical interventions that will maximize the patient's interests, all things considered. Making this determination requires a consequentialist calculation of the potential benefits and risks associated with a given medical intervention, carefully weighing conflicting interests in a way that reflects their relative importance.

The BIS has been codified into law,[7] is common in clinical environments, and is prevalent in bioethics literature and clinical texts (Lo 2009, 267; Jonsen et al. 2006, 97). Despite this prevalence, there is an alarming lack of consensus about how a parent should define her child's best interest. Membership organizations for physicians tend to defer to the parents in determining what constitutes the best interest of the child.[8] This underscores the fundamental tie between the BIS and the nature of the parent-child relationship: the assumption is that a parent will always act in their child's best interest, or at least in a "close enough" approximation of that interest, due to bonds of love and

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[7] It should be noted that the BIS has several applications, including as grounds for legal intervention by the state when it is found that a child's welfare is at risk. For the purposes of this paper, I am solely interested in its application to proxy medical decision-making.

[8] For example, the American Academy of Pediatrics Commission on Bioethics writes, "usually, parental permission articulates what most agree represents the 'best interest of the child'" (American Academy of Pediatrics Commission on Bioethics 1995, 315): Similarly, the American Medical Association writes, "When there is legitimate inability to reach consensus about what is in the best interest of the child, the wishes of the parents should generally receive preference" (American Medical Association 2008).

intimacy (Salter 2012). However, parents are imperfect, and many are motivated by factors other than pure affection for their children. This flaw is not inherent to the BIS itself, but rather in its application.

The BIS has faced numerous critiques: it has been accused of being vague, unknowable, and placing excessive demands on parents. Each of these concerns can be overcome with careful consideration. First, allow me to address the criticism that the BIS is vague (Veatch 1995). This claim seems credible in the sense that appealing to a child's best interest is open to a wide variety of interpretations. However, the "best interest" is distinct from the "best interest standard." There are a variety of proposed iterations of the BIS that attempt to explicitly delineate the appropriate means of maximizing a child's interests (Buchanan and Brock 1989; Kopelman 2005; Drane and Coulehan 1995; Goldstein 1996). The application of each best interest standard requires context-specific judgments, and so they cannot provide an exact calculus for any given situation. However, each attempts to provide (some more successfully than others) substantial enough parameters to guide decision-making in a clinical setting. The issue then is not whether the best interest is vague, but choosing an appropriate version of the standard to guide decision-making.

The BIS may also appear vulnerable to claims that it is impossible to predict future outcomes or events that might influence a child's interests; on this ground, the best interest is simply unknowable. Certainly, the nature of prediction requires us to acknowledge that we will never have the ability to weigh, in a precise manner, how future occurrences will be impacted by present decisions. However, this is not sufficient cause to reject the best interest standard. The BIS requires decision makers to assign appropriate weights to relevant facts and choose the optimal decision for the patient, <u>all things considered</u>. We can interpret <u>all things considered</u> as acknowledging the limitations associated with attempts to predict outcomes or future events. Rather than asking parents to know the precise chain of events that will maximize their child's lifetime interests, it asks that they make the decision that will optimize their child's welfare <u>given the information they have at the time</u>.

Finally, allow me to consider the claim that the BIS makes excessive demands on parents. On my view, the BIS's demand that parents consider the maximization of their child's welfare is not a shortcoming; indeed, this is one of the standard's key contributions. However, I will concede that "best" is an impractical demand. A "best" approach to children's interests may require parents to make unconscionable trade-offs in an attempt to make negligible improvements to their children's interests. For instance, it could be considered "best" for a middle-class parent to transfer custody of her child to a wealthy relative who may be able to marginally improve meaningful aspects of the child's welfare with financial resources.

How can such troubling implications be overcome? First, we can understand the best interest as satisficing rather than maximizing. Jeffrey Blustein proposes such a model, dubbed satisficing parentalism, which permits parents to make choices that serve the needs of their children even when the parents are capable of making an objectively better choice for their child (Blustein 2012). A parent's choice need not be best, but simply good enough. In this context, "good enough" means bringing up a child to the level when they will be fit for independent adult life within their community. This conception calls upon parents to think of serving their children's interests not necessarily in terms of brute maximization, but as thresholds beneath which they may not permit their children's interests to fall.

However, thinking (and speaking) in terms of best interests remains desirable. It is undeniable that "best" is exaggerated language, but this exaggeration should be tolerated because it guides parents in the right direction.[9] Most parents do not aim to be simply "good enough;" they want to be great parents who steadfastly promote the welfare of their children. And certainly, when a parent is in a physician's office discussing surgical options on behalf of her child, she should not be in the mindset of attempting to provide a minimal level of care to that child, or promoting a minimal set of interests. Instead, the parent should remain focused on promoting an ambitious vision of the child's welfare and interests. Best interest language facilitates such a nudge.

The Best Interest Standard is not to be dismissed due to its critics; it has survived because it appeals to the desires of parents and clinicians to promote the welfare of vulnerable children. It remains necessary to give conscientious thought to how the BIS can be focused to better guide the decision-making process. Rather than abandoning the BIS, the remainder of this paper will address ways to improve use of the standard in the context of elective pediatric surgeries.

Section 4: Ethical Consideration of Children's Interests

In the following sections, I will synthesize the discussion above and defend the following thesis: <u>The best interest of the child is the path that serves the child's immediate welfare and, wherever possible, the totality of the child's lifetime interests;</u>

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[9] I would like to thank Jeffrey Brand for his helpful suggestions on this point.

these lifetime interests require priority be given to the child's interest in making self-determined choices when she is able. To this end, I will define several categories of interests held by children. I will then consider what appeals to these interests are made in EPS, offering consideration to both present- and future-oriented interests. Finally, I will propose guidance principles for how to weigh children's sometimes competing interests. A central component of these guidance principles is an understanding that children's fundamental interests generate rights, and that these rights set limits to permissible actions by parents in pursuing medical interventions on behalf of their children.

A. These Are Your Interests

All conceptions of the Best Interest Standard call upon a proxy decision-maker to maximize (or at least strongly promote) the interests of a patient by weighing the projected costs and benefits of a given intervention. Which interests should be maximally promoted vary substantially among different iterations of the BIS, each of which tends to focus on a certain type or combination of interests to be given priority consideration. Before identifying which interests should take priority, it is necessary to identify what interests children hold. To this end, I propose four categories of interests: the first is comprised of those bodily interests that a child needs to survive, and the remaining three includes those cognitive, psychosocial, and autonomy interests that a child needs to thrive. Each interest held by a child can be accounted for within these categories.

The first category, bodily interests, refers to the requirements to sustain life and maintain typical physical functions. Bodily interests include primary needs for healthy food, potable water, protective clothing, adequate medical care, and shelter. The aims of medicine have traditionally been to serve the patient's basic bodily interests by treating illness and injury that pose risks to the biologic functions required to sustain life, as well as addressing sources of physical pain and discomfort (Kass 1975). Bodily interests also refer to the physical capacities necessary to satisfy one's personal needs, including the mobility, gross motor function, and dexterity required to conduct daily life activities, such as feeding and dressing oneself and performing hygienic tasks.

The remaining categories of interests refer to what humans rely on to thrive; these include psychosocial, cognitive, and autonomy interests. Psychosocial interests concern both psychological well-being and the state of interpersonal relationships. This category of interests has to do with the quality of a person's life, especially on a subjective conception of quality of life. The psychological dimension of psychosocial interests concerns emotional welfare, including a common desire to be free from depression, anxiety, or other psychological problems; this reflects the common human desire to feel, for lack of a better word, good (or at the very least, not to feel bad). The social component of this set of interests corresponds to the development and maintenance of interpersonal relationships. These interests concern both relationships that we choose, such as friendships, and those that are the result of forces outside our control, such as biological family.

The third category, cognitive interests, refers to the development of traits, skills, and capacities related to the processing of information and the possession of knowledge. Cognitive interests have clear instrumental value, as they make it possible to perform well in school, excel at work, learn functional life skills and so on. Cognitive interests are also closely related to developing the capacity for autonomy, especially self-determined decision-making. In addition to their instrumental value, cognitive skills hold intrinsic value for many people, who prize obtaining certain knowledge independent of the utility of that knowledge.[10]

Finally, all persons (including children) have autonomy interests. These interests concern a person's ability to pursue projects and plans that are consistent with her values. These interests may hold instrumental value by furthering some of the interests outlined above. However, autonomy interests are commonly understood has having intrinsic value: people value being able to determine and take responsibility for the direction of their own lives, even if their decisions do not always lead to optimal results (Griffin 1986, 53-55).[11]

B. These Are Your Interests on EPS

When EPS is pursued, the justification that is offered typically appeals to the child's interests. Bodily interests tend to be those least promoted by EPS – because these surgeries are not medically indicated, they will not protect or promote a child's basic physical functioning. In fact, bodily interests are often those most risked through pursuit of EPS, as all surgeries carry some level of risk. While the list of possible risks is long and varies significantly between procedures, we can make some general assessments. Surgeries requiring general anesthesia universally carry a small risk of death (Gonzales at

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[10] This reflects an objectivist account of well-being that broadly considers the interests of a typical person while also acknowledging that there will be many outliers whose account of their own interests will differ wildly from the status quo. I believe there is enough flexibility within this approach to adequately consider the well-being of all children who are candidates for EPS. For further discussion, see DeGrazia 1995.

[11] It is out of respect for autonomy that foundational ethical principles call upon practitioners to include patients in the decision-making process. See Beauchamp and Childress 2009.

al. 2012; van der Griend et al. 2011); general anesthesia is also associated with cardiac arrest in pediatric patients (Morray et al. 2000; Bhanaker et al. 2007). All surgeries, including those performed without general anesthesia, carry with them some risk of infection (Sax et al. 2011). Pain is an additional complication that is associated with nearly all surgical procedures. While children tend to accurately report their post-operative pain (Khin Hla et al. 2014), pediatric patients may be undermedicated following surgeries and thus subject to pain beyond their treatment threshold (Gauthier et al. 1998).

Most commonly, EPS is justified as having a prospective psychosocial benefit to the child; I will refer to this subset of surgeries as normalizing EPS. Children with atypical physical characteristics or disability may be subject to teasing or social ostracism. They may suffer from low self-esteem, anxiety, sleep disturbance, depression, or other psychological health problems. These affective states can be associated with harmful consequences, such as disruptive behavior, poor academic performance, or self-harm. Normalizing EPS seeks to prevent such emotional and social troubles. In many cases, parents choose these surgeries on the prediction that others will treat their children badly rather than out of a personal belief that there is anything wrong with their child. By preemptively aiming to minimize social distress, parents intend to maximize their child’s psychological welfare. In these cases, normalizing EPS is meant to improve the overall quality of the child’s life.

Prospective psychosocial benefits are often in conflict with other interests held by children. As noted, there are bodily risks associated with all surgeries. And while certain psychosocial interests are appealed to in EPS, others are risked: many young children who have normalizing EPS are acutely aware of how the surgeries indicate that they are different from their family members and peers, and how they need to be “fixed” as a result (Alderson 2006). This may contribute to a sense of “otherness” that is associated with low self-esteem and social difficulties and has been linked to a sense of ambivalence about EPS by the patients who undergo these procedures (Asch 2006).

Are prospective psychosocial benefits sufficient for parents to authorize normalizing EPS for their children? The permissibility of normalizing EPS is certainly more difficult to determine than the more straightforward question of whether to pursue a medically preventive surgery. In order to account for why normalizing EPS may be ethically problematic while preventive surgeries typically are not, we must determine what distinguishes these two types of surgeries from one another. There are three assumptions made in the pursuit of EPS that are not supported by the kinds of empirical evidence that are typically called for in preventive surgical interventions. These assumptions are that 1) if not prevented, a psychosocial problem will develop; 2) that this problem will require surgery to resolve; and 3) that surgery will be the most appropriate means of addressing the psychosocial problem. Allow me to consider each of these individually.

First, a parent’s decision to pursue normalizing EPS rests on the assumption that, if not prevented, the child will develop a significant psychosocial problem. Earlier in this paper I outlined some of the possible psychosocial problems that children with atypical appearance may encounter. However, normalizing EPS’s appeal to the child’s psychosocial interests relies on an unsupported belief that the child will inevitably develop significant psychosocial problems as a result of her appearance or abilities.

However, a child born with an atypical appearance that is left “uncorrected” is not necessarily a child who is doomed to a life of depression and social troubles. The assumption that surgical means are required to “fix” such children ignores the many people who have led productive, fulfilling and happy lives with a variety of atypical physical characteristics and abilities. To equate being atypical with the promise of psychological problems discounts the experiences of many people who have not experienced such problems despite their atypical appearance or ability.

In contrast, preventive procedures generally require that there be an empirical basis to believe that surgery will have sufficient medical benefit to outweigh its associated risks. For instance, preventive radical mastectomies are performed on certain patients at high risk for breast cancer. But it is not clinically indicated for all women to have their breasts removed to reduce their risk of this cancer. Not even all women with certain risk factors, such as family history, are candidates for preventive radical mastectomies. It is only small subsets of women who carry BRCA genes are considered candidates these operations. There is an absence of a similar empirical basis for normalizing EPS. This is especially evident given the wide degree of variation between persons in terms of their psychological capacity to cope with, and flourish amid, adverse circumstances. While it may be possible to empirically state that a person with particular characteristics is more likely to encounter psychosocial problems, we cannot predict with certainty that this will occur in a given child.

The second assumption in normalizing EPS is that, when such a psychosocial problem develops, it will be serious enough to merit surgical intervention. This is at odds with how many children deal with adversity and the pains of growing up. Across the course of childhood and adolescence, most people will face some kind of psychosocial problem in the form of teasing, situational depression, anxiety, or low self-esteem. Children born with atypical appearance or abilities may encounter these to a more serious degree than others their age. For most young people, psychosocial problems are growing pains – passing struggles that contribute to the development of coping mechanisms. These experiences are often reflected in an individual's self-concept and character. While they may remain difficult or painful for many years, they are frequently overcome. It seems plausible that children with atypical appearance will exhibit the same resilience as other children.

This brings us to the third assumption that supports normalizing EPS, which is that surgery will be the appropriate means of addressing the purported psychosocial need. It is uncommon that high-risk interventions are pursued as a first-line therapy to promote the emotional welfare of children. People struggling with psychosocial problems are ideally ushered through a progression of care starting with the lowest risk to progressively higher-risk interventions. This progression of care is absent in cases where parents seek normalizing EPS as a preventive measure: it jumps directly to a high-risk intervention without first exhausting lower-risk alternatives or establishing that a higher-risk intervention is warranted**.**

In addition to potentially compromising a child's bodily and psychosocial interests, EPS can have a profound impact on a child's autonomy interests – specifically her interest in making self-determined choices – by reducing her future options. When a parent chooses an elective surgery for the child, the child can never choose for herself whether to have that surgery. It is important to acknowledge that the options removed by

EPS are not insignificant. Sovereignty over our bodies is widely recognized as a fundamental interest of all persons. Any permanent modification to the body – whether it is removing a facial birthmark or a malformed limb – infringes on this fundamental interest.

C. Interests and Rights

Like all persons, children hold interests in certain goods and freedoms that are essential not only to sustaining life, but to promoting the kind of well-being that makes that life worthwhile. These fundamental interests provide justification for the existence of certain rights and ground duties to others to honor those rights (Raz 1984). I have already proposed that children's interests should be viewed as threshold in nature; this threshold corresponds to a parental duty to protect and promote their children's interests such that those interests do not fall below a permissible threshold. That permissible threshold should be understood as correlating to a right that protects interests that are fundamental to the child's life and well-being. I will not attempt to defend a complete list of children's rights claims here, but can broadly say that children hold rights in each of the four categories of interests outlined above. These include rights to bodily integrity, physical safety, the bases of emotional well-being, the possibility of pursuing satisfying relationships, adequate education, and the possibility self-determination.[12]

Children's rights set limits on permissible actions others may take toward that child. For instance, a child's right to bodily integrity precludes a person from acting in a

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[12] While this conception of rights holds that interests generate rights, it does not follow that all interests generate rights. A child may have an interest in eating ice cream for dinner, but she cannot claim a right to dine on Ben and Jerry's. Only those interests that are vital, such as those central to human life and flourishing, generate rights (Raz 1984).

way that exposes her to unwarranted physical harm. In some circumstances, it may be necessary for a parent to infringe upon a child’s right – for instance, a child’s right to bodily integrity may be overridden if the child has a health condition that requires an invasive surgical intervention. However, taking the rights of children seriously means that a parent must minimize these infringements (both in number and in scope) while still satisfying her duties to protect and promote her child’s welfare. Because the duty to respect rights is more stringent than the duty to maximize interests, respecting a child’s rights may also limit a parent’s ability to maximize her child’s interests (Brennan and Noggle 1997). Some guidelines for how parents should balance competing rights and interests are discussed below.

D. Weighing Interests and Respecting Children’s Rights

Having laid the groundwork in defining children’s rights, I will now propose guidance principles for how the fundamental interests of children should be weighed by proxy decision-makers when considering EPS. An appropriate place to start is with the child’s present bodily interests. Without protecting these basic elements of life and health, it is impossible to promote the child’s other interests. EPS does not enhance a child’s bodily interests; instead, it can put these at risk. In acting as proxy decision-makers, parents should consider the child’s bodily interests in proportion to the risks to life, comfort, and basic health posed by a given surgery. For instance, an outpatient removal of a birthmark poses a far lower risk of medical complications than a cranioplasty;[13] thus, the weight given to the child's present bodily interests should be lower for the former than the latter. Persons hold future-oriented bodily interests as well. These are the basis for preventive medicine, the adoption of lifestyle choices intended to promote long-term health, and so on. Future-oriented bodily interests should be granted serious weight, but can reasonably be considered subservient to more urgent present interests.

Once the child's vital bodily interests have been secured, a decision-making calculus can proceed to consideration of the child's other interests. Because psychosocial interests play a prominent role in a child's sense of fulfillment and ability to thrive, they should also play a significant part in the decision-making process concerning EPS. Concerns about a child's atypical appearance or ability leading to difficulty forming relationships frequently drive the decision to pursue EPS. A lack of social relationships, or strains in intimate relationships, will likely have a negative impact on psychological health. Low self-esteem, depression, and anxiety are all potential outcomes stemming from social troubles. If a child is presently experiencing psychological problems or distress in her social relationships, then her parent should grant significant weight to her psychosocial interests when considering EPS.

However, the case for placing significant weight on a child's future psychosocial interests is less clear (as I have outlined above). The future psychosocial interests of any person are highly variable and largely unpredictable. There are common desires for stability, comfort, and intimacy that the majority of people share; likewise, we can expect

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[13] Cranioplasty is sometimes referred to as "skull reshaping." This surgery is pursued not only to treat the effects of some illnesses and injuries, but also for cosmetic reasons (i.e., a person opts to take a bone saw to her skull because the bumps on her head are aesthetically dissatisfactory).

most persons to experience periods of emotional highs and lows throughout the course of their life. Correspondingly, the best ways to serve a person's psychosocial needs will vary significantly across time. Given this unpredictability, less emphasis should be placed on maximizing these long-term interests when considering EPS in relation to interests whose future status is more predictable.

There is one factor that reasonably call upon parents to grant significant weight to future psychosocial interests, and that is time. Some surgeries must be performed on children at an early age in order to be effective. One example pertains to children who are born deaf, who must have cochlear implant surgery when they are still in the pre-speech phase of development (around the age of two), or else the implant will be less effective in facilitating language development. The older the child is when receiving a cochlear implant, the less favorable her outcomes (Russell et al. 2013). In cases of this kind, it behooves parents to consider any future psychosocial interests that might be negatively impacted by foregoing a surgery whose efficacy is time-sensitive.

When it comes to cognitive and autonomy interests, EPS requires proxy decision-makers to be forward thinking. Parents must successfully account for a treatment's effects on a child's well-being, including his or her exercise of self-determination, when choosing whether EPS is appropriate. It is instructive to identify the exercise of self-determination as an interest distinct from the development of the capacity for making self-determined choices. With children, it is necessary to consider both their present and future interests in self-determination. In considering a child's present autonomy interests, parents must make a context-specific judgment based not on the choice that must be made, but the individual child's expression of characteristics necessary for autonomous decision-making.[14] For example, more weight should be granted to a fourteen year-olds' desire to have a large birthmark removed from her face than a four year-olds' desire to do the same, because the fourteen year-old will likely exhibit a greater capacity for understanding the risks of the surgery, for weighing the option to have the surgery against the option of not having the surgery, and for identifying the surgery as being consistent with her own values.

It should be clear that respecting a child's present interest in self-determination is not an endorsement of liberationism. Parents are under no duty to grant children, even older children, the right to independently make important decisions on their own behalf. Respect for a child's present interest in self-determination must be a context-specific judgment. If the child's present desire will undermine her fundamental interests in other categories, then it is permissible for a parent to undermine her present autonomy.[15] The responsibility of parents is to conduct a moral calculus that accounts for all of the child's interests, of which present self-determination is merely one.

When considering a child's future autonomy interests, the central consideration should be protecting the child's future self-determination, especially her ability to pursue projects and plans that are consistent with her values. To this end, any decision that would remove an important project or plan from a child's future set of options requires

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[14] I am assuming a gradational model of autonomy where the capacity to make self-determined decisions is context-specific, which views autonomy as points on a scale. This is in contrast to binary, hierarchical models of autonomy, such as that proposed by Harry Frankfurt, which present an agent as being either autonomous or nonautonomous to make a decision based on the relationship of the agent's actions to her own motives. For a more thorough view of such an account, see Frankfurt 1970.

[15] Such paternalistic action is reserved for children based on the presumption that their capacities for the exercise of autonomous decision-making are incomplete. In the case of competent adults, curbing self-determined actions "for their own good" would be impermissible under prevailing ethical standards. See Beauchamp and Childress 2009.

the child's autonomy interests to be weighed more heavily. While it is impossible to predict what a child's future plans may be, a parent can presume that sovereignty over one's body is a matter of fundamental moral importance. Because bodies are tightly connected to how humans experience life and develop and express concepts of self, a parent must acknowledge that actions taken toward her child's body carry significant moral weight. Protecting a child's future autonomy interests means protecting this right to make self-determined choices in pursuit projects and plans about her own body, that reflect her values, when she has the capacity to do so.

Section 5: Portrait of an Ethical Family

While significant consideration has appropriately been given to the interests of the child, it is important to also recognize the dynamics of family that are associated with parental decision-making for minor children. The BIS has been criticized as being too individualistic and failing to adequately account for the interests of parties other than the patient. In particular, it has been argued that maximizing the child's interests in medical decision-making can create untenable demands on parents and families. This section will explore more fully the question of how decisions should be made when the preferences or interests of the family are at odds with those of the child, with a particular emphasis on the duties and rights of parents.

A. Parental Duties

The rights held by children correlate to duties by parents to protect and promote those rights.[16] Parents may not pick and choose which of their children's rights to honor. Parental duties require the satisfaction, rather than the maximization, of a child's interests. These duties also require that adequate justification be provided when a parent overrides any of her child's rights. To respect a child's rights limits the permissible actions that may be taken by parents: while parents are still free to pursue their own goals and plans, the child's rights may take precedence. In these cases, parents are still free to pursue their goals and plans; however, they must identify a path to achieve these goals that does not conflict with the rights of the child.

The specific duties held by parents begin with their responsibility to fulfill their child's primary material needs – for food, clothing, shelter, medical care, and so on. Parents (and other persons) are also barred from abusing, neglecting, or exploiting children. Many parental duties are unique to the role of parent and are not shared by other adults. Among these unique duties is the requirement that parents provide affection, intimacy, and love for their children. Parents also have a duty to treat their children in such a way that valuing the child's well-being honors the unique nature of that child (Mullin 2014).

Finally, parents must raise their children in such a way that their children will possess the skills, competencies, and capabilities necessary to lead independent lives as

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[16] There is a long tradition of viewing rights as directly correlating to duties; see Bentham 1962; Ross 2002. The notion that all rights generate duties is subject to debate; see Lyons, 1970; Raz, 1984. However, even accounts that deny that all rights generate duties generally agree that the parent-child relationship is an instance where the child's rights plausibly generate parental duties.

adults. The preparation for life as autonomous, independent adults is cited one of the central goals of parenting (Bigelow et al. 1988).[17] Parents should engage in autonomy-supporting measures that encourage their children to develop their own goals and values, care stably about some goals, and develop the self-control necessary to pursue those goals (Mullin 2014). Children should be adequately prepared to exercise independent judgment and critical thinking as adults, especially in the design of life plans that are consistent with their values. Parents have a duty to respect the child's right to be free from interference in pursuing goals and projects that are consistent with her values; to this end, parents may not interfere in such a way as to intentionally preclude, for unwarranted reasons, the future goals and projects available to the child. For instance, a parent may not generally deny her child a formal primary and secondary education because doing so will greatly reduce the goals and projects available to the child in the future (such as pursuing higher education or being employed in many kinds of professional positions).

B. Parental Rights

Historically, some have understood parental rights as analogous to ownership rights. On this account, parents hold absolute power over their children, up to the point of having legitimate authority to end their children's lives (Bodin 1976). Today, these views of parental rights have fallen out of favor as substantially lacking in respect for children's moral status, although the debate about the nature of parental rights continues. Some contemporary scholars challenge the idea that a child's interests must override the

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[17] While I am operating under the assumption that the children in question will grow to be independent adults, it is important to acknowledge that even children with disabilities that will prevent them from leading independent lives possess autonomy interests. For further discussion, see Silvers and Pickering-Francis 1995.

interests of her parent. Lainie Friedman Ross adopts this stance in proposing that a parent must only fulfill her child's elementary needs, defined as the basic primary goods essential to life and the development of the skills required to exercise moral character. As long as these needs are met, then it is the parent's right and prerogative to rear her child in whatever way she sees fit (Ross 1998, 5-6). To deny parents this right is to disrespect their personhood and rob them of some of the goods and joys of life. Ross's view permits parents to make intrafamilial trade-offs when considering medical interventions for their children – including trade-offs that serve the parent's interests alone – as long as the child's basic needs are being met. On Ross's account, parents would be within their rights to authorize any of the forms of EPS under discussion here.

Ross's claims are grounded in sound principles. She is motivated, in part, by a belief that children require a "protected period" in which to develop good habits and virtues that will promote their lifetime ability to pursue well thought-out life plans (Ross 1998, 61). Without such a period, children may make reckless decisions that, while satisfying in the present, would reduce their future options. It is for this reason that Ross believes children should not be permitted to make their own decisions about important matters, such as medical interventions. This is an admirable claim that recognizes a child's developing capacities for medical decision-making while observing the importance of a child's developing autonomy. Thus, it is unfortunate that Ross's claim is used to support a conclusion that would permit the severe restriction of a child's future opportunities at the behest of her parents. While Ross's account provides adequate protection for many of a child's fundamental interests, her view fails to acknowledge the full range of a child's interests, which include an interest in developing a reasonably consistent set of personal values, being free to formulate a life plan consistent with those values, and having the opportunity to pursue projects that promote her chosen life plan.

Others have challenged the very existence of parental rights. Phillip Montague rejects the idea of a moral parental right to influence important aspects of their children's lives, claiming instead that parents hold special duties to promote their children's welfare (Montague 2000). Montague's rejection is based on a unique characteristic of parental rights: while a traditional moral right is oriented toward the person whose interests that right protects, parental rights function in a different way. In defending a moral parental right, parent's interests are promoted not because of their own moral importance, but *solely because* parents ostensibly serve the interests of their children. In contrast, a traditional moral right would contend that it is the child who holds the right to her interests, and that parents merely have a duty to promote and protect those interests.

There is, of course, a significant asymmetry in the parent-child relationship: while children's rights generate duties for parents to care for their children, it is not true that parental rights generate similar duties for children. Montague's theory embraces an understanding that the concept of parental rights can be in tension with parental duties. In orienting the right toward the parent, emphasis is placed on what promotes the interest of the parent in her relationship with her child, which is at odds with the notion that the parent has an obligation to promote the welfare of her child. Such a conception makes it plausible for a parent to claim that she is exercising her right when making a choice that imperils the child's welfare, which is at odds with her parental duty despite seeming consistent with her parental right.

Montague holds that parents are not permitted to choose what constitutes fulfilling their duties to promote the welfare of their children. It does not follow that one must deny a parental right to maintain that parents hold special obligations. While a parent may not choose what it means to fulfill her obligations to her child, she is entitled to choose among alternative means of fulfilling those obligations. To accept this right to choose how to serve a child seems consistent with a (limited) parental right.

Michael Austin expands upon the understanding of limited parental rights in arguing that these are best understood as stewardship rights (Austin 2007). Stewards are those who are entrusted with something of great value that they are not owners of. A steward may justifiably be asked to undermine her own interests to promote the interests of her charge in proportion to the value of the entity whom she is stewarding. In this vein, parents can be asked to undermine their own interests because the value of the child in their care is extremely high. The stewardship model acknowledges the power dynamic that is the center of parent-child relationships, which consists of a dominant superior party and a dependent subordinate. Stewardship rights require parents to minimize their authority in the name of their children's future autonomy: since parents will ultimately transfer care of their children's lives to the children themselves, they are called upon to exercise a significant degree of restraint in directing the future lives of their children.

The stewardship conception still grants parents authority to *try* to influence the lives of their children. Parents can do so through satisficing choice mechanisms: when there is more than one way of satisfying a child's fundamental interests, parents should be permitted to choose among alternatives and be protected by intervention from the state or other parties who would call upon them to choose differently. It is through these choice mechanisms that parents may express their own values and character and attempt to influence the values and character of their children. Choice mechanisms reflect the conception that parents are not required to disregard their own interests once they become parents; they are free to pursue their own goals and projects and to try to raise their children in a way that is reflective of their values.

How does this discussion help us understand a parent's role as proxy decision-maker for a child who may undergo EPS? When deciding on the appropriateness of EPS, it is reasonable to ask parents to subordinate their own interests in the surgery. Some aspects of EPS are beneficial to the parents. For instance, hearing parents may prefer cochlear implantation for a deaf child so that they can communicate in their a spoken language; religious members of the Jewish faith receive community benefits from circumcising their infant sons; families who endorse traditional gender conceptions may be most comfortable with sex reassignment of an intersex child; and so on. A stewardship conception requires that parents who are contemplating EPS subordinate their personal stake in the outcomes of the surgery, and instead hold the child's interests as paramount.

C. The Family Unit

Some ethicists claim that the family is so important to human thriving that families are worthy of moral consideration independent of the consideration granted to each member. Hilde Lindemann Nelson and James Lindemann Nelson advance such a view: they claim that the interests that exist within a family unit are not reducible to the interests of individual members, and that the family unit itself is worthy of independent moral consideration (Nelson and Nelson 1995). They propose that instead of being a mere collection of persons with individual interests, a family takes on the characteristics of a sports team – while individual members of a team may have their own goals, the team itself still has a goal of winning. Likewise, a family has interests that are not reducible to the interests of its members.

On Nelson and Nelson's view, modern medicine focuses too much on the needs of individual patients, which can place the goals of the family unit at risk. To remedy this, they call upon practitioners to consider the interests of the family unit as well as the interests of patients under their care when formulating treatment plans. To Nelson and Nelson, this is especially important in situations where the interests of one family member are in conflict with the interests of the family unit. On their view, it is often appropriate to give priority to the interests to the family unit over the interests of a family member. To justify this claim, argue that the intimacy of families creates special responsibilities for members of that family. These responsibilities include providing for family members and sacrificing certain self-interests to promote the interests of the family unit. Nelson an Nelson set limits on these responsibilities: they maintain that no family member be required to make a sacrifice that would be likely to result in irreparable harm (although they do permit risks above the normal level encountered in daily life),[18] and require that a family member cannot be compelled to make sacrifices on behalf of the family unit if she is subject to neglect or abuse.

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[18] This requirement is notably inconsistent with guidelines written by the Presidential Commission for the Study of Bioethical Issues. The Commission has argued against pediatric participation in research where the child will receive no direct benefit from participation in that research and be exposed to more than a minor increase over minimal risk (or the risks associated with daily life for a healthy child living in a safe environment). Although Nelson and Nelson do not address the issue of pediatric participation in research, there is a parallel between the two recommendations as they

To consider how Nelson and Nelson's proposal would play out in the context of EPS, let's consider the Fring family, who are Jewish. Following the birth of their son Gus, Mr. and Mrs. Fring make arrangements for a bris, a ritual circumcision that will confirm Gus as a member of the Jewish faith. Gus's parents and extended family will benefit from Gus's surgery, as the bris conforms to their valued traditions. To the extent that membership in the Jewish faith corresponds to membership in the Fring family, Gus will benefit as well. The Fring family's interests, in this case, will be promoted by circumcising Gus. On Nelson and Nelson's account, it seems plausible that the Fring family could make a rights claim to remove Gus's foreskin in the name of promoting the interests of the family unit, even if the parents were to acknowledge that circumcision will expose Gus to pain and physical risks.

Despite stating that they are promoting the interests of a family unit, Nelson and Nelson's account does not necessarily provide a new space in medical decision-making that respects the moral importance of the family. Instead, their argument is subtly individualistic. We can claim that the family unit is being served by performing a ritual circumcision on Gus, but in reality, it is members of that family that are served, not a nonphysical family unit that is exists separately from its members. Nelson and Nelson effectually claim that it is permissible for one (or more) family member's interests to be given priority over the interests of other family members. The family member that takes priority need not be a child, or even a patient; the only requirement is that her interests are consistent with the broader interests of the family unit.

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both pertain to medical interventions that will have no therapeutic benefit to the patient (Presidential Commission for the Study of Bioethical Issues 2013).

It is easy to see how such an account makes certain members of a family – especially children – vulnerable to exploitation. Coupled with the nonconsensual dimension of family life, these concerns about exploitation are precisely what led to the proliferation of medical ethics accounts that focus on promoting the interests and autonomy of individual patients. Such accounts were created to provide adequate protection for patients against family members who might exploit them at the expense of the patient's well-being. There are power dynamics within families that can lead to the interests of vulnerable members being undermined by more authoritative members. The parent-child relationship is a clear example of such a dynamic. This underscores the importance of giving the interests of children priority wherever possible when making medical decisions that impact the entire family.

Section 6: A New Interpretation of the Child's Best Interest

In synthesizing this comprehensive discussion, a new interpretation of the child's best interest begins to emerge. In order to serve the fundamental interests of the child, it is evident that the optimal path is that which serves the child's immediate welfare in addition to the child's interests over the course of her lifetime. While predictions about how present choices may impact the future interests of children are necessarily imperfect, we can confidently identify the ability to make self-determined choices as a constant, fundamental interest. Respect for this interest supports a conclusion that proxy decision-makers have a duty to grant substantial consideration to the child's ability to make self-determined decisions when she is able. In the case of children who are anticipated to become competent adults, this means parents are obligated to preserve important, optional choices for the child's future exercise whenever possible.

This conception of the child's best interest is in debt to Joel Feinberg's work, which identifies a child's right to an open future (Feinberg 1980). Feinberg recognizes two distinct sets of rights held by children. The first are dependency rights which call upon others to provide them with the basic instruments of life; we can identify these dependency rights as the basis for the parental duties discussed above. The second set of rights is dubbed "rights-in-trust," which are to be preserved for the child to exercise when she is in a position to do so (as an emancipated, competent adult). These include the full range of rights enjoyed by adults, especially the right to self-determination.

It is common for discussion of children's autonomy interests to focus on ways to aid in the development of certain characteristics associated with autonomy, such as the cognitive capacities that facilitate self-determined decision-making (Buchanan and Brock 1989). Other accounts encourage autonomy-supporting measures that foster a child's ability to self-regulate her impulses in pursuit of more cherished goals (Mullin 2014; Joussemet, Landry, and Koester 2008). While both self-regulation and cognitive development are critical capacities for decision-making, we can understand the <u>development of</u> capacities for self-determined decision-making as separate from the <u>exercise of</u> self-determined decision-making. To respect a child's right to exercise self-determined decision-making means preserving important options of choice.[19] Possessing the relevant capacities to make self-determined choices is irrelevant if certain irreversible

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[19] Preserving future choices often means curbing the present autonomy and liberty of children, which is one of the key ways that Feinberg's position, which I expand upon, is distinguishable from Children's Liberationism.

choices are made on the child's behalf before she has the capacity to guide the decision-making process. Both capacity and opportunity need to be present for a person to make a self-determined choice about a given project or plan.

Despite the contributions Feinberg makes in promoting the child's right to self-determination, his position has been subject to critique (Ross 1998; Mills 2003). One criticism is that Feinberg fails to acknowledge that no future is purely open. As a result of time, place, genetics, family characteristics, and pure chance, children are born with a wide variety of capabilities to exercise throughout their life. Parenting certainly plays a role in shaping a child's future choices. We can successfully overcome this objection by thinking about a child's right to an open future not as a right to an exhaustive constellation of options, but rather as precluding the removal of important options from a child's future autonomous exercise. From this perspective, parental choices are able to impact a child's future, but should not consciously preclude the ability of children to make certain decisions as adults.

What does this mean for EPS? First, it is understood that EPS removes an option from a child's future constellation of choices. The question then becomes whether the justification for removing this option is sufficient to override the child's right to make a self-determined choice regarding that option in the future. Therapeutic or preventive surgeries would almost certainly offer sufficient justification to override this right. But a more careful moral calculus that considers the full range of the child's interests must be conducted when a parent is considering EPS. This is due to EPS's status as optional in nature: it does not serve health needs, and does not necessarily promote psychosocial health.

The best interest cannot be one that closes the door to an important future option as a matter of choice. There are many important future options that should be available to children, but those that I am concerned with involve future options about a child's body. Due to the intimate relationship between the physical self and self-concept, options about bodies should always be considered important. We can reasonably assume that any permanent choice about a child's body will impact some aspect of that child's definition of self, and that our definitions of self impact significantly our values, goals, and life plans. Thus, a child's body is a fundamentally important component of her capacity to exercise autonomy.

If a therapeutic or preventive surgery removes an option from a child's future constellation of choices, it is the health need that this surgery responded to removes the important option, not the surgical intervention. For instance, Jane is in a car accident and her right leg is nearly severed. At the hospital, physicians determine that her leg cannot be saved and perform an amputation with the permission of Jane's parents. In this case, it is not the amputation that limits Jane's future options; it is the accident itself.

In contrast, if an important option is removed through elective surgery, it is the choice itself that reduces the future options of the patient. Andrea is born with a malformed right leg. It affects her mobility and appearance but causes her no pain, and she is otherwise healthy. Andrea's parents pursue an amputation of the leg so that Andrea can wear a prosthetic and have a greater range of mobility. In this case, it is Andrea's parents who close the door to Andrea making a decision about her leg as an adult. Like the example above, both sets of parents respond to incidents outside their control when authorizing amputation; however, only Andrea's parents actively *chose* a surgical intervention.

There are instances where a child's right to self-determination can be permissibly overridden. These instances will involve situations where a child's present welfare suffers, and surgery could presumably improve her welfare.[20] In the context of EPS, it seems most plausible that a parent could permissibly pursue EPS on behalf of her child in cases where the child is experiencing real pain – due to harassment which causes extreme emotional distress, for instance (Little 1996). We can identify a reasonable limit to the psychosocial harms a child should be exposed to in the name of preserving her right to future self-determination. To this end, we can state that, when a child's present psychosocial welfare suffers in such a way that she experiences sustained and severe psychosocial difficulty that could be mitigated by EPS, this would provide sufficient justification to override her right to self-determination in regard to this surgery.

There is a nontrivial distinction here, and that is that a child must experience a serious harm, psychosocial or otherwise, for removing an important future option via EPS to be permissible. It does not follow that it is routinely permissible to prevent psychosocial trouble through EPS. Recall that many of these surgeries are performed on infants and toddlers – children too young to even begin to appreciate what it means to be

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[20] What follows draws extensively upon the work of Margaret Olivia Little, which explores the moral permissibility of cosmetic surgery when such surgery seems to be complicit in supporting suspect social norms of appearance. Suspect norms of appearance express preferences for physical characteristics that are disproportionately enforced by society. In the context of our current discussion, these suspect norms could plausibly lead not just to teasing of children with atypical appearance, but harassment and social isolation. While the focus of Little's work is on appearance-enhancing surgeries, I am expanding the kinds of surgical cases under consideration to include those meant to promote norms of ability, which I perceive as being associated with similar means of disproportionate social enforcement as norms of appearance. See Little 1996.

"different." These children could grow up to experience no significant difficulty due to appearing atypical or lacking certain physical capabilities. When surgeries are performed on such children at very young ages, these children are precluded from the opportunity to do determine for themselves whether to pursue these surgeries.

Even in children who are experiencing extreme emotional distress, parents have a duty to first pursue non-surgical means to alleviate that distress. By exhausting lower-risk options first, parents illustrate respect for the totality of a child's interests. For instance, Lydia, a nine year-old with achondroplasia, experienced significant anxiety about her short stature. Talk therapy proved successful in addressing her anxiety about her appearance. In this case, Lydia's bodily interests were respected by not exposing her to the risks and physical pain associated with limb-lengthening surgery. In this way, non-surgical interventions also promote a child's autonomy interests by making an honest attempt to preserve her ability to make self-determined choices about her body when she is competent.

Section 7: Conclusion

A. Our Cases, Revisited

1. Holly: Before she is even taken home from the hospital, Walter and Skyler are considering which of two surgical options to pursue to address Holly's abnormally short leg bones: amputation or limb lengthening. Either choice will permanently remove for Holly the option of choosing an alternative as an adult, including the alternative of leaving her legs unaltered. Leaving Holly's legs unaltered is the most appropriate option, and the one that best respects the totality of her interests. This option also reflects EPS's

optional nature: neither surgery would address present health needs or necessarily serve her psychosocial interests. In fact, both surgical options would subject her to pain before she is even aware that she has a disability.

2. Jesse: As a boy experiencing extreme emotional distress as a result of a cleft lip and palate, Jesse's story exemplifies a legitimate claim to pursue EPS. At present, Jesse's future autonomy interests demand less consideration than his present psychosocial needs. At ten years of age, Jesse has likely begun to develop the characteristics required for him to make a decision of this magnitude, although this development is likely incomplete. He should nonetheless be able to participate in a decision-making process in a way that is meaningful and significant. Finally, Jesse's parents have pursued, and exhausted, non-surgical means to address Jesse's distress before considering surgery, illustrating respect for the totality of his interests.

3. Hank and Marie's child: A growing body of anecdotal evidence (Colapinto 1997), medical study (Meyer-Bahlburg 2005), and ethical analysis (Switzer 2005) indicates that intersex children are not necessarily best served by having sex reassignment surgeries in infancy. Postponing surgical sex reassignment until the child begins to express his or her gender identity is a cautious and acceptable route for parents.[21] This is consistent with a child's right not to have important future options precluded for her through voluntary choices made by her parents. Few options have as much social significance as gender identity, which underscores the importance of postponing surgery for as long as possible.

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[21] Parents would be obligated to utilize surgery to address any medical needs caused by an intersex condition; however, Hank and Marie's child has no such medical needs.

4. Flynn: What is the appropriate course of action for Flynn, the deaf infant whose parents are considering a cochlear implant? Cochlear implants represent a particularly challenging ethical question for two reasons: the timing required for the surgery to be effective, and their non-permanence. On the matter of timing, a parent whose child is born deaf is forced to make a decision about cochlear implantation before the child will be able to participate in the decision-making process in a meaningful way, because the implants are maximally effective in pre-speech children. This means that, no matter what decision is made, a child will not have the opportunity to provide meaningful input about the prospect of surgery. To consider the non-permanence of cochlear implants, it might appear that they do not permanently close a door to a child's future option. Ostensibly, because Flynn could remove an implant later in life, this preserves his ability to choose whether to continue to use the implant or opt to be deaf. However, the insertion of an implant poses practical problems in the sense that he may not be raised to speak sign language or attend schools for deaf children, which could effectively cut him out of experiencing Deaf culture. It is also impossible to ignore the experience of having a sense of hearing and then opting for a life that does not include that sense. Taken in total, it appears that we must understand the choice about cochlear implantation as removing an important future option from the child's future constellation of choices either way. In this way, cochlear implantation is distinct from other forms of EPS.

B. Closing

Most parents seek to protect and promote their children's interests to the best of their ability. However, balancing a child's sometimes competing interests requires a delicate moral calculus that is challenging to execute with precision and confidence. Because children are developing the characteristics necessary for making their own medical decisions, parents have a duty to meaningfully consider all of the child's interests when authorizing elective procedures on behalf of their children. This includes a duty to meaningfully consider the child's future autonomy interests, which are often undermined by elective pediatric surgeries. There are limits to a parent's duty to promote the autonomy interests of her child – namely, that a child's future choices can permissibly be limited if doing so will address a present, serious harm to any of the child's other interests.

The reinterpretation of the child's best interest that I have proposed has several implications that require further consideration. First, this reinterpretation may inform our broader application of the Best Interest Standard: would it stand up to scrutiny when applied to therapeutic and preventive medical procedures as well? Second, this analysis was applied to a subset of minor patients – those who have not reached adolescence, but who are anticipated to become competent adults. How can this understanding of the child's best interests inform the treatment of permanently disabled children who will never attain a typical level of autonomy and independence? Finally, what guidance can this interpretation of the best interest offer when considering interventions for older adolescents who possess the characteristics necessary for medical decision-making but lack the legal authority to do so? These are topics rich for future consideration.

At the very least, we can identify a need to provide further guidance to parents and practitioners on how to interpret the best interest in the context of elective pediatric surgeries. While this paper has focused on the parent's role as proxy decision-maker, healthcare practitioners are well-positioned to provide impassioned account of the child's best interest to guide parental decision-making. Improved training for physicians, nurses, child psychologists, and other health practice professionals may provide the tools necessary to assist parents in a decision-making process that grants adequate weight to the totality of the child's interests**.**

There is also a dearth of instruction from physicians' membership organizations on how to navigate the ethics of determining a child's best interest in the context of elective surgeries. Deference tends to be given to the parent's wishes in determining what constitutes the child's best interest (American Academy of Pediatrics Commission on Bioethics 1995; American Medical Association 2005). But while most parents seek to maximize the well-being of their children, even sincere attempts to promote a child's welfare can conflict with sound ethical guidelines. There is a need for membership organizations to provide guidance to practitioners not only on how they should conceive of the child's best interest, but how to navigate situations where the parent's conception of the child's best interest is at odds with sound conceptions of ethical practice.

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