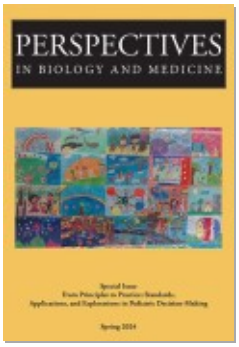
Limits on Parental Discretion in Medical Decision-Making: pediatric intervention principles converge



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Limits on Parental Discretion in Medical Decision-Making

pediatric intervention principles converge

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ABSTRACT Pediatric intervention principles help clinicians and health-care institutions determine appropriate responses when parents' medical decisions place children at risk. Several intervention principles have been proposed and defended in the pediatric ethics literature. These principles may appear to provide conflicting guidance, but much of that conflict is superficial. First, seemingly different pediatric intervention principles sometimes converge on the same guidance. Second, these principles often aim to solve different problems in pediatrics or to operate in different background conditions. The potential for convergence between intervention principles—or at least an absence of conflict between them—matters for both the theory and practice of pediatric ethics. This article builds on the recent work of a diverse group of pediatric ethicists tasked with identifying consensus guidelines for pediatric decision-making.

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In 2023, 17 pediatric ethicists published consensus recommendations for addressing conflicts between parents and clinicians regarding the health care of children (Salter et al. 2023; henceforth, "Consensus Statement"). These recommendations include guidance on when clinicians should seek state intervention to resist or overcome parental decisions to which clinicians object:

> In addition to state mandated reporting requirements, clinicians should seek state intervention when all less restrictive alternatives have been exhausted and a parental decision places the child at significant risk of serious imminent harm, or fails to meet the child's basic interests. (2)

This consensus view about the appropriate use of state intervention in pediatrics is notable because its authors include ethicists who have seemed to disagree on this topic. Those familiar with these debates in the literature may wonder how advocates of different pediatric intervention principles could converge on the above statement. They may also wonder whether broader agreement is possible.

In this article, we explain and defend convergence on intervention-related content in the Consensus Statement. More broadly, we identify potential paths to broader forms of convergence about appropriate triggers for state intervention in pediatrics. (Note that we focus only on questions about when to seek interventions—for example, from state actors; we do not address what intervening actors ought to do.) First, we review background axioms about decision-making in pediatrics. Second, we explain three leading pediatric intervention principles. Third, we identify paths to convergence and resolutions to conflicts that are largely superficial.

Background on Pediatric Decision-Making

Parents and guardians in the United States have legal rights to make most decisions for their children, including medical decisions, even when they contravene clinician recommendations (see, for example, *Meyer v. State of Nebraska* [262 U.S. 390 (1923)] and *Pierce v. Society of Sisters* [268 U.S. 510 (1925)].) There are many ethical reasons to support wide parental discretion in child-care decisions. Parents or guardians are the primary responsible agents for caring for children, usually know what is best for them, and have a right to raise children in accordance with their values (Buchanan and Brock 1989). Additionally, parents and children benefit from the intimacies of family life that parental discretion enables.

Accordingly, ethical theorizing about pediatric decision-making starts with the presumption that parents' informed consent (or what the American Academy of Pediatrics calls "parental permission") is necessary for children to receive medical treatment (Katz, Webb, and AAP Committee on Bioethics 2016). The goal of an intervention principle is to identify the limits of that presumption—that is, to

identify the scope of parental rights to make decisions on behalf of their children (Gillam 2016).

Parents May Choose Any of Several Reasonable Options

We can begin to identify the limits of parental discretion by looking initially at easy kinds of cases. First, there is no need for clinicians to intervene when parents grant permission to one of the beneficial treatment options that a clinician is willing to offer, even if parents do not accept the option that the clinician deems optimal (Kon and Morrison 2018; Wyatt et al. 2015).

For example, even if the clinician recommends surgery, parents should be able to choose medical management for their child's early-state uncomplicated appendicitis if the clinician believes that both treatment options would be reasonably beneficial. Clinicians in this case may have an ethical responsibility to steer shared decision-making towards the surgical option, if they think that is the best choice. But parents may make the ultimate decision, even if clinicians judge it suboptimal (Opel 2018).

Parents May Not Commit Abuse or Neglect

Clinicians often have legal obligations to intervene to protect children. These legal obligations identify relatively clear and uncontroversial limits of parental discretion. For example, all 50 states in the US require clinicians to report suspected abuse or neglect of children (Child Welfare Information Gateway 2019). Mandatory reporting requirements vary between states, as do their evidentiary thresholds, but all states recognize these limits to parental discretion.

Among other requirements, mandated reporter laws require clinicians to seek state intervention if parents are withholding medically indicated treatment from a child with life-threatening conditions. For example, suppose parents decline to provide insulin to their diabetic child or refuse to administer short-acting beta2-agonists (SABAs) when their child has symptoms of an acute asthma attack. Clinicians would likely have an obligation to report such instances of suspected medical neglect to state authorities if they cannot persuade the parents to provide indicated treatments.

Parents May Not Demand Nonbeneficial Interventions

Beyond their legal obligations to report suspected abuse or neglect, there are two further contexts in which clinicians have ethical obligations to resist parental discretion. First, clinicians should generally refuse to provide nonbeneficial interventions, even if parents demand them. For example, if a child has a viral infection, clinicians should usually not prescribe antibiotics, even if parents insist (Bosslet et al. 2015). Similarly, clinicians should not accede to parental demands for tracheostomy or percutaneous endoscopic gastrostomy (PEG) tube placement

for the purpose of facilitating discharge from the hospital if the child-patient is very likely to die in the hospital in hours to days.

State intervention is rarely necessary in such cases, because clinicians have robust professional, institutional, and legal rights to decline to provide inappropriate treatments to patients. It is usually *parents* who would need to seek state support if they wanted to further pursue treatments that the child's clinician refused to offer.[1] Thus, while there are important ethics questions about clinician refusals of parental requests (Kukora et al. 2019), these are not usually questions about when clinicians should involve state intervention. We therefore set them aside.

Parents May Not Refuse Some Beneficial Interventions

Unlike refusing parental demands for nonbeneficial treatments, which ordinarily does not require state intervention, clinicians may need to seek intervention when parents refuse beneficial therapies.

For example, consider a parent who refuses to authorize analgesia during the suturing of a deep wound on their child's hand, and who insists that she will take the child home from the hospital if the clinicians will not close the wound without pain management. If the clinicians cannot persuade the parent to accept effective pain management for the child, they may have to seek (or at least threaten) intervention from state actors, including child protective services (CPS) or the courts. The authors of the Consensus Statement focus on this kind of case, and we do also.

Admonitions Regarding State Intervention

There are two important caveats regarding the involvement of state actors in resisting parental permission. First, the threat of involvement from the state is sometimes sufficient to successfully counter parental resistance. We therefore treat threats of state involvement as tantamount to the actual involvement of the state, particularly in ethical terms, since either way, state power is leveraged against parents. Second, the involvement of state actors to prevent risks and burdens to the child can impose substantial burdens on families and children and can damage the clinician's relationship with both the parents and the child-patient. Clinicians should not underestimate the short- and long-term harms of state intervention. Accordingly, clinicians should seek state interventions only when, as the Consensus Statement says, "all less restrictive alternatives have been exhausted and a parental decision places the child at significant risk of serious imminent harm, or fails to meet the child's basic interests" (Salter et al. 2023, 2).

[1]Counterexamples include futility cases in the UK, where it is common for clinicians to go to court for authorization to refuse nonbeneficial treatments requested by parents. Even in the US, clinicians will sometimes petition the court to appoint a guardian in response to inappropriate parental requests, rather than merely refusing those requests.

Intervention Principles in the Literature

In their groundbreaking work, *Deciding for Others: The Ethics of Surrogate Decision Making* (1989), Buchanan and Brock distinguish four elements of surrogate decision-making, including clinical decision-making for child-patients: *underlying ethical values* are the core commitments that inform ethical decision-making; *authority principles* identify who makes decisions; *guidance principles* direct their choices; and *intervention principles* identify when clinicians, state actors, and others should take decision-making away from those with presumptive authority to decide. Below we address the fourth element of surrogate decision-making—intervention principles—in the case of pediatrics.

The pediatric ethics literature appears to contain substantial conflict about which intervention principle is most appropriate in determining the appropriateness of state involvement in pediatrics. McDougall and Notini (2014) identify nine different ethical frameworks, including: the best interests standard (Kopelman 1997; Pope 2011); the harm threshold (Diekema 2004, 2011); constrained parental autonomy (Miller 2003; Ross 1998); choice within reasonable alternatives (McCullough 2009); responsible mode of thinking (Schoeman 1985); the not unreasonable standard (Rhodes and Holzman 2004); the rational parent (Cooper and Koch 1996); the balance of costs and benefits (DeMarco, Powell, and Stewart 2011); and the decisional capacity of the minor (Kipnis 1997).

We limit our attention to the first three intervention principles—best interests standard (BIS), harm threshold (HT), and constrained parental autonomy (CPA)—because these are, by far, the most commonly embraced intervention principles in the literature, they are seemingly divergent, and their chief advocates were among the authors of the Consensus Statement. These were also the three intervention principles mentioned in the AAP's most recent statement on decision-making in pediatrics (Katz, Webb, and AAP Committee on Bioethics 2016). Moreover, it is not clear how conceptually distinct the other six intervention principles are from each other or from the three we focus on. For example, it seems likely that the ideas of a "rational parent," a "responsible mode of thinking," and "reasons that other reasonable people could refuse" ultimately reduce to claims about whether parents should be permitted to harm or otherwise fail to protect the interests of their children. That is, making sense of these other six principles will likely reduce to something very much like the BIS, the HT, or CPA.

Paths to Convergence or Conflict Avoidance

The three most embraced intervention principles can be briefly summarized. According to the BIS, clinicians should seek state intervention in pediatrics when doing so would promote the child-patient's interest. According to the HT, state intervention is appropriate when failure to intervene would cause significant risk

of serious harm. According to the CPA, intervention is warranted when a child's basic interests or rights are threatened by failure to intervene.

One way to think about the differences between these three intervention principles is to view them as existing on a spectrum, corresponding to approval of interventions for parental refusals that are more or less suboptimal for children. On this account, advocates of all three principles can endorse intervention to prevent significant risks of serious harms. Advocates of the CPA and BIS can endorse interventions to protect a child's basic interests and rights (even in the absence of significant risks of serious harms), but only advocates of the BIS would also endorse interventions when parental refusals fail to promote a child's best interests. Such a view envisions the debate about intervention principles as a disagreement about how bad a parent's refusal must be for the child before intervention is justified.

There is something to be said for thinking that the HT is merely a partial expression of the CPA, and that the CPA is merely a partial expression of the BIS. Among other things, this account can explain why advocates of the BIS and the CPA were able to sign the Consensus Statement, which seems to express the core of the HT. While advocates of the BIS and the CPA may have wanted to call for *more* interventions, they could at least accept *all* the interventions that the HT advocate embraced.

But this interpretation is not consistent with what advocates of different intervention principles say about their own views. Whether the HT is a partial expression of the CPA, and the CPA is a partial expression of the BIS depends on (1) whether there are basic interests or rights that it would not be harmful to deprive children, and (2) whether children have interests that are not basic interests or rights. Notably, Diekema (2019) and Ross (2019) appear to disagree about the former claim: Diekema asserts that something is a harm if and only if it is a violation of a right or a basic interest, while Ross asserts that there are some rights and basic interests that children can be deprived of without causing harm.

More generally, a complete determination of what any intervention principle requires—and, therefore, whether it conflicts with another intervention principle—involves the meanings and scope of core terms about which people disagree. For example, Brummett (2019) has argued that there is reasonable disagreement about what constitutes a "harm," and therefore about what the HT requires. It follows that disagreement about the meanings of these normative terms also affects whether one accepts that the HT overlaps partially or completely with the CPA or BIS.

Beyond disagreement about the meaning of core terms, advocates of the three intervention principles often seem to be addressing different problems, assuming different background conditions, or focusing on different kinds of interventions. They may even mean different things by the term "intervention principle." By unpacking these kinds of equivocation, we can identify a more accurate and nu-

anced account of the relationship between the three intervention principles. This work illuminates greater convergence than is apparent in the existing literature and provides stronger guidance for most kinds of cases that clinicians face.

Different Kinds of Intervention Principles

As noted above, pediatric *guidance* principles identify the goals of clinician recommendations and parental decisions, while *intervention* principles identify the limits on parental decision-making. One resolution to the apparent conflict between two intervention principles emerges if one of the principles is really a guidance principle masquerading as an intervention principle, and if its practical application does not differ from the practical application of the true intervention principle.

For example, following Brock and Buchanan (1989), Diekema (2019) suggests that the BIS should be the guidance principle in pediatrics, the HT should be the intervention principle, and that the HT coheres with the BIS (as a guidance principle) around questions of state intervention. The details of Diekema's view illustrate that he embraces the HT as a means of best balancing the benefits and burdens of possible interventions to ensure that interventions promote a child's interests. State interventions cause harms, so they can be in children's interests only when the intervention is necessary to prevent imminent serious harms and is proven to be efficacious (Diekema 2004). Indeed, even initiating a state investigation process—for example, following an initial CPS notification—can cause substantial harms to patients, families, and the clinician's relationships with both. This is the case even if the state investigation does not result in restraints on parental choices.

Contrast Diekema's account of the HT with Loretta Kopelman's (1997) embrace of the BIS. Kopelman states that the threshold for state intervention in pediatric decision-making usually requires parental actions or inactions that place children in danger or cause serious harm. This sounds like Diekema's HT. But Kopelman insists that the BIS constitutes an intervention principle because it is in the best interests of the child for the state to intervene in such cases (see also Kopelman 2007). On this point, there does not appear to be much practical difference between Kopleman's and Diekema's positions, but only in what they mean by the term "intervention principle."

Advocates of the HT may be tempted to say that Kopelman has made a category mistake because she seems to have labeled the BIS as an intervention principle while really treating it as a guidance principle. But another way to interpret what has happened is that people who advocate the BIS as an intervention principle are not relying on Buchanan and Brock's (1989) framework or terminology. By "intervention principle," perhaps they mean a principle that identifies the fundamental values that dictate when intervention should occur. Such a principle would identify the philosophical and ethical basis for interventions but would not

provide concrete guidance for when and how to resist parental decisions. This kind of grounding intervention principle would stand in contrast to something like Diekema's HT, which identifies the specific conditions for permissible interventions under particular contexts.

Accordingly, if the BIS were understood as a grounding intervention principle, and the HT were understood to be more of a practical intervention principle, then there need not be any important conflict between them. Of course, the distinction between grounding intervention principles and practical intervention principles may just use different language to recapitulate Buchanan and Brock's distinction between guidance and intervention principles. But inasmuch as some people advocate the BIS under the banner of an "intervention principle," identifying the slipperiness of this term does important philosophical work.[2]

Different Background Institutions

Another path to convergence can be found in the different assumptions that advocates of intervention principles make about the existence and efficacy of legal institutions that protect children's rights and interests. For example, it may do little good (and may do substantial harm) for a clinician to seek state intervention to protect a child against risks to rights or interests that the government lacks the will or resources to protect (Goldstein, Freund, and Solnit 1984). Accordingly, even if clinicians believed that the government should intervene to protect such interests, they will accept that they should not seek intervention to protect such interests if the government will not protect them. This would harm the family, the child, and the clinical relationship, without any countervailing benefit.

For example, in a country like the US that does not affirm human rights for children, but only protects them from serious medical harms (and even then, selectively), the threshold for state interventions that are likely to benefit child-patients is likely to be closer to that picked out by the HT than by CPA or BIS.

In contrast, in countries that have ratified the UN Convention on the Rights of the Child (1989) and have incorporated its principles into domestic legal obligations (Hoffman and Stern 2020), clinicians may have good reason to predict that state intervention will be beneficial to children at something closer to the level picked out by the CPA or BIS. Therefore, someone who advocates for the HT, while assuming background institutions within contexts such as the US, nonetheless may be able to accept the CPA or BIS as more appropriate in different sociopolitical contexts. Similarly, someone who advocates for CPA or BIS

[2]The distinction between grounding principles and rules for action is a hallmark of ethical theory, but it is also frequently neglected or confused. For example, the criterion of right action for utilitarianism—to maximize happiness, impartially considered—does not, by itself, identify any rule for action (*pace* many critics of utilitarianism), but is instead a standard for justifying such rules. Indeed, Henry Sidgwick (1874) famously argued that utilitarianism requires most people to continue to follow rules of conventional morality rather than to directly aim at utility maximization through their individual acts.

in countries whose legal institutions protect children's rights and basic interests may be able to accept the HT as a threshold for state intervention in countries like the US.

Convergence can also be possible if advocates of different intervention principles intend for their principles to speak to more or less idealized circumstances. Someone who endorses the CPA or BIS in the US context may mean for their endorsement to be aspirational. They may think that the US *should* develop legal institutions to protect children's rights and basic interests and that, if such institutions were developed, then clinicians should seek state intervention at the higher threshold that CPA and BIS entail. If that were the case, then someone who endorses the HT for clinicians in the US likely does not disagree in principle with advocates of those other standards. The HT advocate may share their hope for the future, but they may endorse the HT as part of their practical resignation to their country's current, limited ability to protect a broader set of children's rights and interests.

Consider, for example, Johan Bester's (2018) claim that clinicians and the government should intervene to ensure that children are vaccinated, even against committed parental refusal. Bester argues that these interventions are justified because they are in a child's best interests. The kind of compulsory vaccination that Bester advocates has only rarely been attempted in the US, and it has never received widespread political support (Colgrove 2006). Accordingly, such interventions are only possible—and, therefore, only beneficial for children—in very different sociopolitical contexts. In the contemporary US, pediatricians usually should not call CPS merely because parents refuse recommended vaccines (Diekema 2004). Inviting state intervention in such cases would likely cause substantial harms without creating compensatory benefits.

As the vaccination example shows, some versions of the BIS may not be not action-guiding for clinicians in certain contexts. If we understand the primary goal of an intervention principle to be offering practical guidance for clinicians responding to problematic forms of parental decision-making, then the supposed conflicts between HT, CPA, and BIS may turn less on the endorsement of different values than on the presence of different practical conditions.

Different Interventions for Different Kinds of Suboptimality

Acts of intervention against parental permission are not monolithic, but instead include options along a spectrum. These span direct state involvement, quasi-governmental interference (like ethics committee review), and other discursive strategies that may disrupt or redirect parental decisions (Ross 2019).[3] Different

[3]The line between state and non-state interventions is not always clear. For example, when a private hospital ethics committee has final unreviewable decision-making power authorized by statutory law, it may act as a state power when it intervenes; see, for example, *T.L. v. Cook Children's Medical Center,* 607 S.W.3d 9 (Tex. App. 2020).

intervention principles may converge, or at least not conflict, when they are invoked to justify different kinds of interventions (Navin and Wasserman 2019). For example, the HT most clearly identifies when state agencies, such as courts or CPS, may intervene to prevent parental refusal of recommended treatments (or when clinicians may invoke this kind of state power). This principle shines a spotlight on imminent, significant harm, emphasizing interventions when children's well-being is critically threatened and the typical kind of intervention it references is correspondingly overt.

The CPA may seem to widen the intervention lens. In addition to the kind of state interventions that the advocates of the HT focus on, it also highlights interventions such as ethics committee reviews and physician second opinions (Ross 2019). These are still "interventions," in that they bypass or at least press against default shared decision-making processes between parents and the clinician. Accordingly, advocates of the CPA or BIS may not be rejecting the HT when they are arguing that non-state-based interventions can be justified even when a child is not at significant risk of serious harm. They are instead introducing kinds of interventions about which the HT typically has been silent.

Similarly, the BIS advocate may believe that there are *even more* interventions that ought to be considered, such as using framing nudges that emphasize mortality (such as "20% of children die") to discourage some treatments and using framing nudges that emphasize survival rates ("80% of children live") to overcome parental resistance to other treatments (Blumenthal-Barby and Opel 2018). Such interventions may not overtly challenge parental decision-making authority, but they are still interventions because they are nonrational (and, often, manipulative) means by which clinicians can intervene to prevent problematic parental preferences from being implemented. Advocates of the BIS may argue that such interventions are justified by kinds of parental refusal that would not support state intervention or ethics committee review. Accordingly, rather than disagreeing with advocates of either the HT or CPA, these BIS advocates would instead identify thresholds for forms of intervention that advocates of those other principles did not address.

Different Degrees of Existing State Involvement

We can further question supposed differences between the BIS, HT, and CPA by looking at differences in the degree to which the government is already involved in making decisions on behalf of children. Some defenders of the BIS frame its application within contexts involving state supervision, like foster care, or in scenarios marked by parental disputes, such as post-divorce conflicts (Pope 2011). One of their reasons for endorsing the BIS in these contexts is because that principle is a widely endorsed *legal standard* for the government to make decisions for children when the government has already been tasked to do so.

However, in such cases the state has either already donned the guardian hat or has been thrust into an arbitrator role. The BIS may be the most appropriate standard in such cases because the state likely cannot otherwise instantiate familial values and preferences and so ought to default to the best interests of the child to guide decisions. In contrast, most pediatric medical decisions involve children who are under their parents' care, rather than state supervision. The HT's attention to the harms associated with *introducing* state intervention indicates that advocates of this principle aim to speak to such contexts, rather than to disputes involving existing state intervention. Therefore, conflicts between the demands of the HT and the BIS would seem to be less likely or less serious when children are already under state supervision or when the state is otherwise already a decision-maker.

Conclusion

In this article, we identify substantial potential for convergence and for the resolution of apparent conflicts between different pediatric intervention principles. The best interests standard (BIS), harm threshold (HT), and constrained parental autonomy (CPA) principles can appear to be distinct and conflicting guidelines, but a deeper analysis reveals that any conflicts are often more apparent than real. This result matters for the theory of pediatric ethics, as it demonstrates that greater consensus exists than may have previously been appreciated, and it may matter even more for the practice of pediatric ethics, as it grounds a more unified approach to the challenges presented by the interplay of parental discretion, clinician recommendations, and the well-being of child-patients.

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