City University of New York (CUNY)

CUNY Academic Works

Publications and Research

New York City College of Technology

2019

Intervention principles in pediatric health care: the difference between physicians and the state.

D. Robert MacDougall

CUNY New York City College of Technology

[How does access to this work benefit you? Let us know!](#)

More information about this work at: https://academicworks.cuny.edu/ny_pubs/714

Discover additional works at: <https://academicworks.cuny.edu>

This work is made publicly available by the City University of New York (CUNY).

Contact: AcademicWorks@cuny.edu

Intervention principles in pediatric health care: the difference between physicians and the state

D. Robert MacDougall*

dmacdougall@citytech.cuny.edu

Abstract According to various accounts, intervention in pediatric decisions is justified either by the best interests standard or the harm principle. While these principles have various nuances that distinguish them from each other, they are similar in the sense that both focus primarily on the features of parental decisions that justify intervention, rather than on the competency or authority of the parties that intervene. Accounts of these principles effectively suggest that intervention in pediatric decision making is warranted for both physicians and the state under precisely the same circumstances. This essay argues that there are substantial differences in the competencies and authorities of physicians and the state, and that the principles that guide their intervention should also be conceived differently. While both the best interests standard and the harm principle effectively incorporate important aspects of physicians' ethical obligations, neither adequately reflects the state's ethical obligations. In contrast to physicians, the state has major obligations of distributive justice and neutrality that should form an integral part of any proposed ethical principles guiding state intervention in pediatric decision making. The differences are illustrated by examining recent cases involving parental refusal of chemotherapy in aboriginal Canadian communities and parental refusal of blood transfusions by Jehovah's Witnesses.

Keywords Best interests standard; Harm principle; Pediatric decision making; State intervention; Liberalism; Justice; *Parens patriae*

Both the law and much of the bioethics literature consider children incompetent to make their own health care decisions, particularly when they are very young. Consequently, health care decisions for children must be performed by a surrogate, and parents usually perform primary surrogate decision-making duties on behalf of their children. However, surrogate decision making on behalf of children differs from decision making performed on behalf of previously competent patients. For previously competent patients, surrogate decisions should follow a "subjective" standard, relying on the patient's previously expressed values,

* New York City College of Technology, CUNY, 300 Jay Street, N611, Brooklyn, NY 11201

preferences, or wishes. But in the case of never-competent patients such as children, information about subjective values and preferences is lacking, so surrogates should instead rely on judgments about the patient's objective interests. Accordingly, parents making health care decisions have traditionally been urged to make their decisions on the basis of the "best interests" of the child, objectively considered [1, 2].

Although parents perform the surrogate role by default, proceeding with a positive treatment plan usually requires the cooperation of physicians. Before cooperating with parental decisions, physicians should, as a general rule, make their own independent judgments about the consequences of the treatment plan for the objective interests of the child patient. Physicians will often agree with parents that their decisions further the objective interests of the child. However, in some cases physicians may determine that parental decisions do not advance the objective interests of the child, or may even represent a serious setback to those interests. Depending on the case, physicians may decide to avoid cooperating with parents or may even decide to actively intervene.¹ For example, they may report parents for medical neglect or seek a court-ordered mandate for treatment. However, most commentators agree that physician interventions are justified only when parental decisions fail to meet some minimum standard. Commentators have debated whether this minimum standard is best included under the rubric of the "best interests standard" (BIS) [3, 4] or whether this standard is best described by a more recently proposed "harm principle"

¹ In many jurisdictions, it should be noted, physicians have very little discretion about which cases to report. Their legal duties in this regard are outlined in "mandated reporter" requirements. However, the topic of this essay is physicians' ethical duties, not their legal ones. So for now, I leave open the question of whether and under what circumstances physicians have an ethical obligation to report cases of neglect.

[5-8]. But on all accounts, physician decisions about intervention should proceed on a somewhat different basis than that which is considered ideal for surrogate decisions.

In those cases where physicians decide to intervene by appealing to the state, one more decision must yet be made before the outcome is determined: the state must decide whether it will intervene in the child's health care. The literature generally suggests that the principle forming the basis for the state's decision should be the same as that proposed as the basis for the physician's decision—namely, either the BIS [9, 3, 4] or the harm principle [5, 6, 10].

In this essay, I do not say much more about the principles guiding parental decision making, but instead examine the principles guiding decisions two and three—that is, the principles guiding physicians and the state, respectively, when they consider intervention in parental decision making. I argue against the general thrust of the literature suggesting that both physicians and the state ought to decide whether to intervene on the basis of the same or similar principles. Physicians and the state are fundamentally different actors, with very different competencies and roles, and—correspondingly—duties and obligations. I argue that neither the best interests standard nor the harm principle is a suitable basis for determining whether the state should intervene in some particular case. This is not because there is something wrong with one or the other of these principles as a guide for interventions *per se*. On the contrary, I argue that two features shared by these principles are defensible when informing *physician* ethics and are assets when employed in clinical decision making. However, the features of these principles that are assets when employed in physician decision making are liabilities when employed in state decision making. Although I do not outline a complete theory of state intervention, I do suggest that the state has two major

obligations—obligations of distributive justice and neutrality—that must temper its obligation to promote or protect the objective interests of any particular child.

Principles for state intervention: the debate

As one might expect based on the literal meaning of “best interests,” the BIS was understood by early commentators to require maximizing benefits to the child. On this traditional definition, the BIS requires decision makers to determine the net benefit (i.e., benefits subtracting risks or harms) of each of the available options, and then select the one that maximizes net benefits for the child [1, 11].

Early commentators also generally claimed the BIS could justify intervention into parental decision making [1, 2]. However, despite the “maximization” definition relied upon by these early commentators, they did not necessarily think that intervention was justified whenever parents failed to maximize the interests of their children. For example, Allen Buchanan and Dan Brock argue that parental failure to maximize the interests of their children is an overly broad justification for intervention [1]. Such an interpretation of the BIS would require intervening on behalf of children whose families cannot afford to optimize their educational opportunities, for example, which seems absurd. Instead, intervention should be based on judgments about (a) the severity and likelihood of the harm and (b) “evidence that most informed and reasonable persons ... would choose differently” [1, p. 145]. Loretta Kopelman, likewise, argues that basing intervention on the “maximization” definition would be problematic. Instead, in cases where intervention is contemplated, the BIS can be considered as a “threshold for intervention and judgment” [2]. Kopelman says that when the BIS is used as a threshold for overriding “parental authority, the state must establish, often by clear and

convincing proof, that the child has been harmed or is in danger of suffering serious harm” [2, p. 275]. For Kopelman, the BIS functions in different ways depending on the context, and it can help justify intervention when parental decisions are likely to impose severe harm on a child.

While many agree that state intervention is justified when parental decisions seem likely to cause significant harm, several commentators have pointed out that it is not clear how this view can be understood to follow from the best interests standard [5, 6, 12, 7]. The problem is that the term “best interests” on its most natural interpretation suggests maximized benefit for the child, not mere prevention of severe harm.

Because of this problem, Douglas Diekema offers an alternative “harm principle” [5]. His harm principle is based on a principle of the same name proposed by John Stuart Mill. On Diekema’s formulation, the harm principle asserts that “parental decisions that do not significantly increase the likelihood of serious harm as compared to other options should be tolerated” [5, p. 252]. The primary difference between the harm principle and the best interests standard, according to Diekema, is that the former makes clear that intervention in parental decision making is justified only when parental decisions threaten to visit a child with significant likelihood of serious harm. Simple failure to do what is in the child’s “best interests” is not sufficient justification for intervention.

Some commentators have been persuaded by Diekema’s harm principle, and have offered further applications and defenses of the principle [7, 13, 8]. However, several vigorous responses to Diekema’s harm principle, all favoring continued use of the BIS for intervention decisions, have also been offered [3, 4, 14]. Instead of wading into the debate between these two sides, which is beyond the scope of the present essay, I want to highlight

two assumptions, apparently common to both sides of the debate. First, as noted above, there is actually widespread agreement that intervention is justified when harm to the child is projected to cross some threshold. The disagreement is primarily about whether this threshold is best described under the best-interest paradigm or under the harm principle.

Second, and perhaps less obvious, is the fact that commentators on both sides of this debate give little explicit attention to the identity of the parties intervening in parental decisions. Emphasis is usually placed on features of parental decisions that justify intervention, rather than on detailed description of the duties or role of those who would intervene. So advocates of the BIS, such as Buchanan and Brock [1] and Kopelman [2], argue that intervention is warranted whenever projected harm crosses some threshold, and they seem to apply this standard indiscriminately to the state, the physicians, and various hospital personnel. If the standards apply in different ways to the physicians versus the state, they do not discuss this.

Advocates of the harm principle apply it in a similarly indiscriminate way. While Diekema originally proposed the harm principle to explain the proper threshold for state intervention [5], he also claims the harm principle should determine when physicians should seek state intervention [5, 6]. Since then others have further applied the harm principle to physician decision making [7, 8, 15]. Proponents of both the BIS and the harm principle seem to agree that the same basic principles—whatever they are—justify intervention, regardless of whether it is performed by physicians or the state.

Physicians' judgments about intervention

While there has been little discussion of the distinct responsibilities of the parties who intervene, a compelling case can be made that both the BIS and the harm principle give a plausible account of when physicians should intervene in parental decisions. In what follows, I consider two features shared by these principles and discuss some reasons these common features are advantages for any general principles guiding *physician* intervention decisions.

Whose interests? Interests of the individual child

First, both the BIS and harm principle require physicians to prioritize the interests of the individual child. Buchanan and Brock clarify the extent of this prioritization when they argue that the BIS requires considering only the “self-regarding” interests of the child [1, p. 132]—meaning that surrogates should not consider a child’s interest in the good of others, such as an interest in the well-being of immediate family-members. While it is extremely common for competent persons to take an active interest in the well-being of those they care about, Buchanan and Brock reason that if there is sufficient evidence to determine that the child takes such an interest in the well-being of others, then the “substituted judgment standard” would be the appropriate decision making standard [1, p. 112]. But since children are not competent to offer evidence of their interest in the well-being of others, it is best to assume only self-regarding interests on their part.

Erica Salter, in her review, finds that most commentators have similarly held the BIS to require “individualistic” decision making on behalf of children [12]. Salter claims that one account—Kopelman’s—allows decision makers to construe the child’s interests more broadly and consider the child’s interests in the well-being of others. Kopelman says, for example,

that providing an expensive medication for a child might be in the best interests of the child, but may not be obligatory if it would bankrupt the family [9]. However, Kopelman does not argue that this is because of the child's interests in the financial solvency of the family. Instead, it is because the best interests standard poses only a *prima facie* duty to act in the child's best interests, a duty which may not actually obtain when it competes with other more stringent duties (as in this example). So (and as Salter argues elsewhere [16]), the dominant conception of the BIS has placed emphasis on the self-regarding interests of the individual child.

Some authors have held that the harm principle differs from the BIS because it allows decision makers to take into account interests of persons beyond the individual child. For example, Lynn Gillam argues that the harm principle effectively creates a zone of parental discretion, within which parents can balance the interests of one child against others in the family [7]. This is thought to be an advantage of the harm principle over the BIS, since such balancing decisions are a necessary part of parenting more than one child.

It is not clear that there is any genuine difference in this regard between the BIS and the harm principle when considered in their threshold or limit-setting function, however. As seen above, proponents of the BIS do not typically support intervention in just any decision that is not in the literal best interests of the child. Intervention is justified only when parental decisions cross a threshold of acceptable harms. In this sense, *both* the BIS and the harm principle allow parents some latitude to make tradeoffs between the interests of different family members. Moreover, in the event that a decision represents a significant likelihood of severely harming the child—that is, when a decision does cross the threshold—*neither* the BIS nor the harm principle will allow such weighing or tradeoffs between the child's interests

and the interests of others. For example, neither principle clearly requires intervention in a parental decision to take the family to a hospital to give support and companionship to a seriously sick child, despite the fact that such a decision may expose siblings to a variety of infectious diseases and so not be in their literal “best interest.” But both principles would likely require intervention in a case where parents pursue transplantation between siblings that is likely to cause lifelong damage to the donor, regardless of the benefit procured for the recipient sibling. So it is most accurate to say that both principles suggest non-intervention if tradeoffs do not cross the threshold; and both principles suggest intervention if tradeoffs would result in significant harm to a child.

Is it good that both principles require giving priority to the interests of individual children? The priority placed on the child patient’s individual interests is, I think, defensible—at least, when practiced by *physicians*. The priority given to the individual child reflects physicians’ obligation, grounded in their profession, to prioritize the interests of individual patients. This obligation to the individual patient usually means prioritizing the patient’s interests over and above the interests of the treating physician or others in the health care facility; the interests of the party responsible for paying for health care; and even the interests of other patients. In this way, the BIS and the harm principle are no different than the “subjective” standards usually used on behalf of adults [17]. In each case, surrogates—including physicians, whether they are in the role of surrogate or whether they are cooperating with surrogates to execute a treatment plan—must privilege the interests of the individual patient.

Privileging patient interests is not an unconditional duty, and physicians will sometimes have to temper their advocacy for individual patients in order to accommodate the rights or

interests of others. However, any such limitations on the physician's obligation to advocate for the interests of individual patients are usually conceived of either as (1) limitations that have been publicly imposed to protect others' rights (see, e.g., [18, p. 218-242], [1, p. 205-6]) or as (2) rare exceptions involving extremely serious interests of others (see [17]). So although there are certainly limits to physicians' obligation to prioritize the interests of their patients, these limits are usually understood to leave intact the physician's primary ethical obligation to prioritize the interests of individual patients, since those limits are either imposed from the outside or function as exceptions to the general rule. The BIS and the harm principle, insofar as they both require privileging the interests of the individual child, fit comfortably with the physician's obligations to privilege the interests of individual patients and are, in this respect, highly defensible as principles governing physician interventions.

Which interests count? Instrumental, non-ultimate interests

Second, both the BIS and the harm principle allow physicians to consider only a restricted set of the child's interests.

Initially, it may seem that authors run the gamut on the interests they consider relevant to intervention decisions. Salter, in her review of the BIS, notes that authors have variously considered the physiological, psychological-emotional, relational, or cognitive-developmental needs and interests of the child [12]. Diekema likewise seems open to considering a range of interests, specifically mentioning the child's interests in obtaining primary goods² or those things instrumental for achieving ultimate interests [5, 6]. Gillam, elaborating on the harm

² "Primary goods" is John Rawls' term for "things that every rational man is presumed to want," among which Rawls considers "rights and liberties, opportunities and powers, income and wealth" [19, p. 62]. They are thus essentially the class of instrumental, non-ultimate interests.

principle, claims that it recognizes “all the interests”—not just “medical interests,” but “social, psychological and emotional interests as well” [7, p. 3]. While descriptions of relevant interests are fairly broad and somewhat disparate, the descriptions seem united on one thing: they consider only what might be called *instrumental* interests or values and avoid considering *ultimate* interests or values. Here I highlight two kinds of ultimate interests that commentators typically do not consider in their evaluations of the child’s interests: spiritual interests and cultural interests. I now turn to consider how these kinds of interests sometimes affect parental decisions, and how they have been addressed by commentators, before evaluating whether it is justifiable for physicians to ignore these interests when considering intervention.

By “spiritual interests” I mean a child’s interest in non- or other-worldly goods, such as the inheritance of eternal life, avoidance of damnation, good standing or favor before God/the gods, and so forth. It is well known that parental medical decisions are sometimes heavily influenced by an understanding of the child’s spiritual interests. Some of the most visible cases are those involving Jehovah’s Witnesses. Some Jehovah’s Witnesses believe that receiving a blood transfusion may result in loss of eternal life, even if the transfusion occurs in childhood.³ If transfusions really could result in loss of eternal life, parental refusals are perfectly rational. Eternal life is presumably a more substantial benefit than a temporary, mortal life; if loss of mortal life is a severe harm, then loss of eternal life is even more so. If

³ There does not necessarily seem to be a 1:1 correlation between accepting a blood transfusion and loss of eternal life, although the church has drawn a connection between these in the case of children. According to the Watch Tower Society, Jehovah’s Witnesses “know that if they violate God’s law on blood and the child dies in the process, they have endangered that child’s opportunity for everlasting life in God’s new world. Their love is not motivated by overriding emotion that seeks satisfaction only at the moment, but their love is deep, seeking the everlasting welfare of their loved ones” [20, p. 55-6].

forfeiture of eternal life were to count in either a best-interests or harm calculation, it would likely trump all countervailing interests.

If commentators were concerned about *all* of the child's interests, or even just the most important ones, one might think that the child's interest in eternal life would be a major point of discussion in the literature. After all, reaching a conclusion about either the best interests of the child or what ultimately harms the child depends crucially on whether this belief about the afterlife is correct. However, almost no commentator on these cases directly addresses whether this belief is correct, and almost no one factors the child's interest in the afterlife into an analysis of these cases.⁴

Similarly, commentators have also been unwilling to consider interests that are cultural in nature. By "cultural interests" I mean interests in goods that are valuable for someone solely because that person belongs as a member to a particular community. These interests are non-instrumental in the sense that they are not necessarily good for any further thing. Consider two recent cases involving Canadian aboriginal girls, the cases of Makayla Sault and J.J. [23, 24]. The cases were remarkably similar. Both involved Canadian aboriginal girls living in neighboring communities in Ontario. Both girls were diagnosed with acute lymphocytic leukemia in 2014, and for both girls, physicians predicted that survival was probable with

⁴ Diekema provides a striking example of this approach. Diekema argues that the harm principle clearly requires intervening in cases involving Jehovah's Witnesses who refuse blood transfusions on behalf of their children [5]. Diekema's reasoning goes like this: blood transfusions are, in many cases, the only way of avoiding death; consequently, for children who need them, transfusions are a major benefit. Moreover, the risks associated with blood transfusions are "minimal" [5, p. 255]. Consequently, to deprive the child of a transfusion is to visit the child with great net harm. Intervening in parental refusals is thus clearly recommended by the harm principle. But what can Diekema mean when he says that the risks of receiving a blood transfusion are "minimal"? If the parents are correct, the risks associated with receiving the transfusion are devastating. Diekema never explains this point. His treatment is typical of the bioethics literature surrounding this topic, in that it excludes consideration of spiritual interests without going into great detail about why such considerations should not count in the analysis of the child's interests. For exceptions to this general trend, see [21, 22].

chemotherapy but impossible without it. In each case, the parents made the decision to withdraw the child from chemotherapy and pursue traditional aboriginal treatments instead. We do not fully know the reasons for either family's decision. In one case, the case of J.J., the court decision suggests that part of the reason for choosing traditional medicine over chemotherapy was semi-religious: according to that document, the Haudenosaunee believe that their traditional treatments were handed down from the gods [25]. However, nothing in the case suggests that the use of chemotherapy is forbidden or that traditional treatments are mandatory. Instead, the court documents suggest that there is something intrinsically valuable about receiving traditional medicines, which have been "key to the health and survival of Haudenosaunee as a nation" [25]. According to Karen Hill, an aboriginal physician familiar with the case, the issue "is about indigenous people reclaiming their wholeness as people. This isn't about religion; it isn't about choice. It's about being who we are" (quoted in [26, p. E153]). The views of commentators on these cases were somewhat mixed, but those who employed the BIS generally did not explicitly factor in the girls' interests in living according to cultural customs [27, 28].

What, if anything, justifies physicians in excluding ultimate interests, such as spiritual or cultural interests, from determinations about harm to children? One might argue that to allow such interests to play a part in physician decision making is to actively endorse the legitimacy of those interests. Insofar as a treating physician does not actually affirm the existence or value of spiritual or cultural interests, the physician should refrain from cooperating with decisions based on them. But this argument seems problematic, in that it suggests physicians should utilize their own spiritual or cultural values when deciding what counts as a child's objective interests.

A better reason for requiring physicians to base intervention decisions on the instrumental interests of the child is found in the limited professional competency of physicians. If physicians can be said to have a distinct set of professional duties, these presumably follow from their special training and expertise in medicine. This expertise extends to the cure or mitigation of pain and disease, the extension of physical life, and even to some extent the cognitive-developmental, emotional, and social needs of patients (in this case, children). Physicians' training and subsequent expertise in these limited, instrumental interests justify their limited professional authority to diagnose and treat disease and to alleviate pain or discomfort. But nothing in physician training or practice gives physicians any special competency in ultimate interests, such as spiritual or cultural interests. This lack of competency is one reason why physicians cannot override the wishes of adult patients. If physicians lack the competency to determine the ultimate interests of adults, it is unclear why they would have the competency to determine the ultimate interests of children.⁵

The fact that physicians have some special standing to intervene in cases of pediatric decision making does not mean that their professional competency extends to matters of ultimate interests either. As a general rule, physician authority to intervene is limited to making a report or petition to the state for intervention. The physician's authority to intervene in these ways is entirely compatible with the physician's expertise in medical matters: the physician reports decisions she considers detrimental to the child's health. But physicians cannot go further than this on their own authority. Physicians who actively intervene without first obtaining authorization from the state can be held liable for battery.

⁵ This is not to say that if physicians did have training in spiritual or cultural interests, they could make decisions for either adults or children. It is just to emphasize the complete absence of any reason for thinking that physicians, as a group, have the competency to decide about the ultimate interests of anyone, regardless of age.

This limitation on the social authority of physicians fits naturally with the limited competency we take them to have. We limit physicians' authority to intervene in this way because we do not take them to have broad competency to decide what is in the ultimate interests of anyone, including children. Physicians have no competency to make an "all things considered" decision on behalf of children, and this is the reason that they have no further authority than merely to report or petition the state for active intervention.

State judgments about intervention

The BIS and the harm principle, then, both require that intervention decisions be made according to the individual interests of the child; and they prioritize the child's instrumental interests while tending to dismiss ultimate interests, such as interests that are spiritual or cultural in nature. I have argued that these features of the principles are defensible when applied to physicians because they capture certain features of physicians' professional obligations and competency. However, although these features are assets in principles governing physician behavior, they are liabilities when employed in state decision making.

Whose interests? States and distributive justice

As argued earlier, focus on the individual child is a virtue in physician decision making. While physicians have obligations to respect the rights of others, these obligations exist most plausibly as a set of restrictions or limitations put on physicians by society, the profession, or the state. The physician's first obligation is to the individual patient.

The state however does not have a similar first obligation. In contrast, the first obligation of the state is more plausibly conceived as the protection of equal rights. The state must treat individuals as equals and should not privilege the interests of any particular party.

Such a claim relies, necessarily, on some theory about the ultimate role and authority of the state. Here I draw on liberal theories of the state. Liberal theorists have typically explained the authority of the state by beginning from the premise that individuals are moral equals in some respect. Unlike divine right theorists, who claim that the sovereign is essentially unequal to subjects and consequently can rule them by right, liberals argue that persons have no innate political authority over one another. But if individuals are moral equals, how can the exercise of political authority of some over others ever be justified? Liberals typically assert that political authority is justified when it protects the rights and liberties of individuals. In this way, the exercise of political authority does not indicate unequal moral status because it is instead conceived of as protecting moral equality.

The state's duties are a consequence of this limited authority. Because the state's authority is based, fundamentally, on its protection of equal rights, the state also has a duty not to systematically privilege the rights or interests of preferred individuals or groups. To do so would violate its duty to protect the rights of all as moral equals.⁶

For these reasons, the state—unlike physicians—should not treat individual children as isolated cases and decide cases based on a particular child's interests alone, but must instead consider the child as one among many toward whom the state has equal duties. If the state

⁶ Similarly, the state should presumably not privilege its own interests on the liberal view either. This would seem to call into question the United States Supreme Court's claim in *Prince v. Massachusetts*, 321 U.S. 158 (1944), that it can restrict the freedom of minors because it has an interest in the kinds of citizens they turn into. However, proponents of the BIS and the harm principle have not claimed that intervention is justified when it is in the interest of the state, so I will not pursue this question further here.

should consider an individual child's interests—as both the BIS and the harm principle advocates propose—it must presumably balance these interests against the interests of others to whom the state is equally obligated. Saying that the state has an obligation to protect interests equally is, essentially, affirming that the state is bound in such decisions to be constrained by distributive justice.

How might the state's obligation to achieve distributive justice affect decisions about intervening in a particular medical case? Kopelman advances the case of children who need transplants [9]. The state makes decisions about how to allocate scarce organs and cannot make this decision on the basis of any one patient. Policies put in place are conceived to be as fair as possible. Nevertheless, the decisions made in many of these cases must necessarily cross the threshold allowed by either the BIS or the harm principle because choosing some as organ recipients results in the death of others who would have survived had they been chosen instead. Yet this does not necessarily mean there is anything wrong with the state's decision. Contrast this with the physician who decides her patient does not really deserve an organ as much as some other child. Perhaps this physician is merely expressing approval of what she takes to be fair state policies regarding organ allocation. The physician who decides on her own authority that her patient does not deserve an organ as much as someone else has probably failed in her capacity as physician. The physician would be blameworthy in a way that the state is not, even though they both reach the same conclusion.

What about cases not having to do with scarce resources—for example, cases where the question is whether to grant a court-ordered mandate for a life-saving treatment? Why would the state need to consider anyone else's interests when deciding whether to issue a court-ordered mandate?

Even in these cases, the state should consider whether the rights or interests of third parties are adversely affected. Consider again the case of the Canadian aboriginal girls. After Makayla Sault returned home, McMaster hospital referred the case to the Children's Aid Society, which has the authority under provincial law to remove children from their homes and place them in protective custody. In response to learning of this development, Sault's mother recruited others from the New Credit First Nation to form a "Makayla defence force," which she claimed was ready to resist the Children's Aid Society if necessary [29].

Physical confrontation seems drastic but is understandable when considered in light of the historical relationship between the Canadian government and First Nations people. Beginning in the 1940s and not fully ending until the 1990s, the Canadian government systematically removed thousands of First Nations children from their families and relocated them to residential schools. According to the recent *Truth and Reconciliation* report documenting the legacy of this policy, in 1953, around the height of the residential school movement, 4,313 of 11,000 aboriginal children in residential schools were there on the grounds that they were suffering "neglect" at home, and by 1960 it was estimated that 50% of the aboriginal children in the schools were there "for child-protection reasons" [30, p. 4]. Many of the relocated children were sexually abused in their new homes, and it has been estimated that the policy resulted in 6,000 child deaths [31]. Chief Bryan Laforme explained the meaning that Makayla's community associated with her proposed removal by child protection services: "We're not going to allow any other agency to come in and apprehend our children. We went through that in the '40s and '50s and we're not going to allow that again" [29].

The state should, in this situation, give careful consideration to stakeholders beyond the child at risk. For one thing, a court-ordered mandate could easily produce unintended consequences. While it may succeed in saving one child's life, the means by which that end is achieved would likely further distance Makayla's community from health care institutions,⁷ and ultimately worsen overall health outcomes. Even a very crude utilitarian analysis would have to question the wisdom of granting a court-ordered mandate in this case. The state has a duty to consider the long-term social consequences of its interventions in a way that individual treating physicians do not. In a similar vein, the state might also consider whether issuing a court-ordered mandate would exacerbate health disparities. Canadian First Nations communities have notoriously poor health outcomes compared to other Canadians [33, 34], and further damaging trust in the state and Western health care institutions could be predicted to exacerbate these disparities.

While the cases of J.J. and Makayla Sault vividly illustrate the ethical problems with state decision making focused on individual patients, these problems are not unique to cases involving First Nations communities. Many other cases involving refusal of treatment also involve religious, ethnic, or cultural minorities, and the state should consider the effects of court-ordered mandates on relevant communities in these cases as well.

Parens patriae and the state's duty to care for children

It might be objected that the doctrine of parens patriae requires the state to make the interests of the child paramount. The parens patriae doctrine asserts that the state is the

⁷ Such an effect was predicted by Judge Murray Sinclair, chair of the Truth and Reconciliation Commission. According to Judge Sinclair, speaking with reference to the case of J.J., "when the medical community asks the legal system to force parents to submit their children to treatments they do not support, 'it now just generates more distrust'" [32].

“father of the nation,” and thus forms the legal basis on which the state has often overruled parental decisions it views as harmful or potentially harmful, including refusals of medical care on behalf of children.⁸ While the doctrine is sometimes construed as merely giving the state authority over children without guardians, the doctrine actually endows the state with a far more expansive authority. This can be seen in early elaborations of the doctrine, which argue that parental authority is delegated to parents by the state as a “trust,” with the state retaining ultimate authority and responsibility over children.⁹ In fact, this more expansive definition is at work whenever the doctrine is used to overrule decisions by a child’s actual parents or guardians: if the state cites its parental authority as justifying intervention in the decision of actual parents, the best explanation is that the state’s parental authority is the more foundational of the two. If the state has ultimate parental authority over all children, then others (including, presumably, both physicians and parents) are at most surrogates or fiduciaries on behalf of the state. And if that is the case, then any differences between state authority, physician authority, and parental authority are best seen as differences of degree rather than kind, in contrast to what I have been arguing here.

My treatment here assesses pediatric decision making from an ethical rather than legal perspective. So the question is not simply whether the state claims *parens patriae* authority over children, but instead whether such a claim is ethically plausible. I will briefly outline two reasons for thinking it is not.

⁸ The *parens patriae* doctrine was utilized in *Prince v. MA*, which set the precedent that is sometimes cited by courts intervening in medical decisions, such as those involving Jehovah’s Witnesses’ refusals of blood transfusions on behalf of their children.

⁹ These elements of the doctrine were elaborated in *Wellesley v. Wellesley* 4 Eng. Rep. 1078 (H.L. 1828) and *Ex parte Crouse* Whart. 9, at 11 (Pa. 1839), as explained by Jeffrey Blustein [35].

First is the problem that if the state does bear ultimate responsibility and authority over children, this is not reflected in the vast majority of our laws and social conventions. The state does not assign parents as the caretakers of their children. Parents who give birth to a child are, by default, the caretakers of the child. If the state were the ultimate caretaker of all children, surely it would have the responsibility of assigning children to the most capable parents; or at the very least, of assessing parental competence prior to allowing parents to have or keep their children. Although such schemes have been proposed (for example [36, 37]), the state does no such thing. While the state does occasionally remove children from the care of their parents in extreme cases, this does not entail that parents receive their authority from the state. As Ferdinand Schoeman [38] argues, the fact that I may permissibly intervene if I see my neighbor attacking her child with a knife does not entail that my neighbor gets her parental authority from me.

Moreover, parents bear virtually all of the economic, emotional, psychological, and physical burdens associated with raising their own children. These are not “delegated” to them in any meaningful sense by the state, but are theirs by default. And parents have a huge amount of discretion for raising their children according to their own conception of the good. Parents may restrict the social and sexual lives of children; they can hold children to idiosyncratic standards of behavior; they can indoctrinate them with their religious views or impart other comprehensive doctrines, such as atheism, or various philosophical theories. This authority to direct children according to the *parents’* conception of the good or comprehensive doctrine cannot easily be understood as a mere extension of, or fulfillment of a fiduciary duty on behalf of, the state: if the state has a duty and a subsequent authority to raise children according to its own comprehensive doctrine, then allowing parents to raise

children according to their *own* views would be a dereliction, rather than a delegation, of this duty. Social and legal conventions strongly suggest, then, that whatever the relationship between the state and children, it is not one of general parental authority.

Second, the *parens patriae* doctrine is also difficult to reconcile with liberal political commitments. As I have just noted, parents have the authority to raise their children according to their particular conception of the good or comprehensive doctrine, and may even attempt to persuade their children to adopt these. This authority is arguably partially constitutive of the parental relationship itself. Consider the term “paternalism” (from Latin *paternus* “of a father”)—often used as an epithet to describe an objectionable relationship between adults, such as when a law is passed forcing people to act in ways “for their own good.” Although it is objectionable when adults impose their conception of the good on other adults, it is necessary for parents to do this for their children: parents who entirely fail to direct their children according to the good are not being tolerant or open-minded, but negligent. While parents have both authority and a responsibility to direct their children according to the good, on the liberal view, the state has no authority to direct citizens according to a conception of the good. The state has a duty to remain neutral with respect to competing conceptions of the good and should not direct citizens on the basis of comprehensive doctrines (one reason for this is explained in the following section). So there is a *prima facie* incompatibility between the liberal state and the *parens patriae* doctrine (see [35]). Moreover, if the state cannot direct citizens in a conception of the good, this offers further reason for thinking that parental authority is not delegated by the state: the state cannot delegate an authority it does not have [38].

The idea that the state has a general parental relationship with children in its jurisdiction does not find support in either social convention or in major normative political theories, then. These are ethical reasons for thinking that the state should not pursue the interests of particular children in the way a parent should, extravagant claims about *parens patriae* authority to the contrary notwithstanding.

Which interests count? States and neutrality

As argued earlier, both the BIS and the harm principle suggest that physicians should make determinations about intervention on the basis of a limited set of interests, including a variety of instrumental interests but excluding consideration of interests or values that are ultimately or inherently good, such as spiritual or cultural interests. These limitations are appropriate because physicians have no special competency in non-instrumental interests or ultimate values and because physician “interventions” are reports that do not directly determine the course of treatment, at least not without ratification by the state.

State intervention cannot be understood in such an innocuous way, however. When states intervene, their interventions—whether in the form of issuing court-ordered mandates or declaring a child “in need of protection”—are final. They are final because the state will, if necessary, enforce its decisions coercively. Because the state’s actions are coercive in a way that decisions by other parties, such as physicians, are not, principles governing state intervention must also be different from those governing private parties. According to many

political liberals, the coercive aspect of state action means that the state has a special duty to remain neutral (in some respect¹⁰) between competing moral and religious views.

Consider, for example, Rawls' political liberalism [40]. According to Rawls, there exists a "reasonable pluralism" of views about what is of overall value in life, or what Rawls' calls "comprehensive doctrines." These comprehensive doctrines include a variety of religious, moral, or philosophical doctrines about what actually is the case. On Rawls' view, this reasonable pluralism is the inevitable result of human reason working in a free society. Reasonable pluralism is inevitable because of the epistemological difficulties involved in settling on a comprehensive doctrine: in order to arrive at a settled view, one must take on what Rawls calls the "burdens of judgment," such as balancing competing value claims, making judgments based on limited experience, or making sense of complicated and conflicting empirical information. The burdens of judgment entail that no comprehensive doctrine can be conclusively demonstrated to others on the basis of reason alone [40].

Reasonable pluralism thus poses a significant moral problem for coercive laws based on comprehensive doctrines. This is the problem of legitimacy: how can free and equal people be forced to obey laws based on reasons or views that they reasonably reject? Rawls' answer to this question composes a significant portion of his liberal theory of justice.

Reasonable pluralism also poses a challenge for state interference with medical decisions made on behalf of minors. Parental decisions that seem harmful are often—though, of

¹⁰ I use the term "neutrality" here to refer to a variety of normative responses to the problem of pluralism that all involve some form of "not taking sides." Not all liberal thinkers have understood neutrality in the same way, and of course they develop a variety of accounts of what neutrality in this broad sense entails. Some liberal perfectionists have been critical of the idea that the liberal state can be neutral, for example. Whether the state can be absolutely neutral is beside the point being made here, though. Most forms of liberalism have at least wanted to protect individuals' rights to live according to conscience and religion. For more on this, see [39].

course, not always—grounded in comprehensive views about what is of overall or ultimate value in life. The state cannot simply act as though those views are false any more than it can simply act as though those views are true. Without further explanation or justification, such interference runs up against the problem of liberal legitimacy and may even violate the state's duty to remain neutral. For example, overriding decisions by Jehovah's Witnesses to refuse blood transfusions on behalf of their children seems to require violating Rawls' principle of state neutrality, as I have argued elsewhere [21].

While liberal theories of justice tend to take the problems of moral and religious pluralism very seriously, both the BIS and harm principle solve the problems pluralism raises by simply failing to address them. Major proponents of both principles either constrain the relevant considerations to purely "instrumental" interests or simply fail to address the role that spiritual and cultural interests should play in intervention decisions. As I have argued, these constraints are an advantage for physician decision making. A state, on the other hand, needs a substantially more developed explanation or defense when it makes decisions that override citizens' spiritual, cultural, or moral beliefs because the state acts coercively and has a subsequent obligation to remain neutral with respect to comprehensive doctrines.

The harm principle as a liberal principle

I have argued in this section that neither the BIS nor the harm principle is suitably neutral from a liberal point of view. But one might object that Diekema's harm principle avoids this problem. After all, it is based on Mill's harm principle, which Mill developed as a principle for justifying the exercise of coercion. Diekema holds, as does Mill, that the state should be tolerant of a wide pluralism of moral and religious views and should limit individual activities based on these views only when they would cause harm to others. Diekema's view, like Mill's

harm principle, seems to be a paradigmatically liberal response to the problem of pluralism, not a violation of the liberal requirement of state neutrality.

Nonetheless, the extent to which Diekema's harm principle is incompatible with Mill's harm principle has not been widely appreciated. Mill's view cannot support Diekema's application of it. Mill does say that harm—either to oneself or to others—can justify state intervention, and this is the part of Mill's account that Diekema utilizes. However, in his understanding of harm, Diekema makes reference to the *objective* interests of the child. As argued earlier, pediatric decision making is necessarily concerned with objective interests because children are not competent to make decisions about what is in their interests.

But when Mill talks about harm, he does not mean harm to objective interests. He cannot mean objective interests because the major point of *On Liberty* is to defend the idea that we cannot interfere with others in order to promote their objective interests. Says Mill regarding the kinds of reasons that justify interfering with another person,

His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or forbear *because it will be better for him to do so, because it will make him happier, because, in the opinions of others, to do so would be wise, or even right*. These are good reasons for remonstrating with him, or reasoning with him, or persuading him, or entreating him, but not for compelling him, or visiting him with any evil in case he do otherwise. [41, p. 13] (emphasis added)

It is rather an individual's liberty to pursue subjective interests—interests as she or he understands them—that Mill protects. Mill protects the liberty to pursue subjective interpretations of one's interests in “self-regarding actions” of course, but also extends this liberty to interactions with others, so long as those interactions occur “with their free, voluntary, and undeceived consent and participation” [41, p. 16].

On Mill's view, then, persons are free to harm themselves or others—where “harm” is considered in an objective sense as setting back someone's objective interests—provided that the person being harmed consents. Consent is the sign that a person has determined that the interaction is in his or her subjective interests. But this is the reason that Mill's harm principle cannot be applied to children. Children cannot make authoritative determinations about their own subjective interests. Consequently, a child's consent does not render an action taken towards her non-harmful; nor does lack of her consent necessarily mean that actions taken towards her are harmful. Because Mill is fundamentally concerned with privileging subjective interests over objective ones, Diekema's extension of the principle to persons not yet capable of authoritatively determining their own subjective interests is deeply problematic.

The distinction between subjective and objective interests also explains why Mill's view is a liberal one, while Diekema's is not obviously so. By privileging subjective interests, Mill makes it possible for people to live according to a variety of views about what is valuable or good, and so Mill's view effectively accommodates pluralism. By referring to objective interests as the basis for state intervention, Diekema's view, however, does not.

Conclusion

I have not argued in this essay for any final set of principles for state intervention in pediatric decision making. Instead, I have given an account of some of the major distinctions between the normative requirements incumbent on physicians and the state, respectively, and argued that bioethics intervention principles—namely, the BIS and the harm principle—cannot serve as the ethical foundation for state intervention. Bioethics principles prioritize the needs of

the individual child, while state decision making cannot prioritize individual parties because it must be bound by considerations of distributive justice. And bioethics principles constrain decision making to instrumental goods and interests, while the state must consider the whole range of values before intervening, since state intervention is inherently coercive.

These considerations suggest that there may be occasions in which physician “intervention”—in the form of reporting or seeking a mandate—is ethically warranted, while state intervention is not. Intervention is justified for the former by principles that arguably bind physicians, but it may not be justified for the latter because of the very different principles that bind the state. That the principles binding physicians and the state in these cases differ sharply should not be surprising, though: physicians and the state are fundamentally different kinds of agents, with different competencies and correspondingly different kinds of social authority.

Acknowledgments

I would like to thank audiences at the American Society of Bioethics and Humanities and the Canadian Bioethics Society for comments on presented versions of this paper, and to the reviewers and editors at *Theoretical Medicine and Bioethics* for their helpful comments, insights, and criticisms on earlier versions of this manuscript.

References

1. Buchanan, Allen E., and Dan W. Brock. 1989. *Deciding for others : The ethics of surrogate decisionmaking*. Cambridge England ; New York: Cambridge University Press.
2. Kopelman, L M. 1997. The best-interests standard as threshold, ideal, and standard of reasonableness. *The Journal of Medicine and Philosophy* 22 (3):271-289.
3. Pope, Thaddeus Mason. 2011. The best interest standard: Both guide and limit to medical decision making on behalf of incapacitated patients. *The Journal of clinical ethics* 22 (2):134-138.
4. Birchley, Giles. 2016. Harm is all you need? Best interests and disputes about parental decision-making. *Journal of Medical Ethics* 42 (2):111-115.
5. Diekema, Douglas S. 2004. Parental refusals of medical treatment: The harm principle as threshold for state intervention. *Theoretical Medicine and Bioethics* 25 (4):243-264.
6. Diekema, Douglas S. 2011. Revisiting the best interest standard: Uses and misuses. *The Journal of clinical ethics* 22 (2):128-133.
7. Gillam, Lynn. 2015. The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. *Clinical Ethics* 11 (1):1-8.
8. Wilkinson, Dominic, and Tara Nair. 2016. Harm isn't all you need: Parental discretion and medical decisions for a child. *Journal of Medical Ethics* 42 (2):116-118.
9. Kopelman, Loretta. 2005. Rejecting the baby doe rules and defending a "negative" analysis of the best interests standard. *The Journal of Medicine and Philosophy* 30 (4):331-352.
10. McDougall, Rosalind J., and Lauren Notini. 2014. Overriding parents' medical decisions for their children: A systematic review of normative literature. *Journal of Medical Ethics* 40 (7):448-452.
11. Beauchamp, Tom L., and James F. Childress. 2013. *Principles of biomedical ethics*. 7th Ed. New York, NY: Oxford Univ. Press.
12. Salter, Erica K. 2012. Deciding for a child: A comprehensive analysis of the best interest standard. *Theoretical Medicine and Bioethics* 33 (3):179-198.
13. McDougall, Rosalind J. 2016. Indeterminacy and the normative basis of the harm threshold for overriding parental decisions: A response to birchley. *Journal of Medical Ethics* 42 (2):119-120.
14. Bester, Johan C. 2018. The harm principle cannot replace the best interest standard: Problems with using the harm principle for medical decision making for children. *American Journal of Bioethics* 18 (8):9-19.

15. Winters, Janine P. 2018. When parents refuse: Resolving entrenched disagreements between parents and clinicians in situations of uncertainty and complexity. *American Journal of Bioethics* 18 (8):20-31.
16. Salter, E K. 2014. Resisting the siren call of individualism in pediatric decision-making and the role of relational interests. *The Journal of Medicine and Philosophy* 39 (1):26-40.
17. Strong, C. 1993. Patients should not always come first in treatment decisions. *The Journal of clinical ethics* 4 (1):63-65.
18. Daniels, Norman. 2008. *Just health: Meeting health needs fairly*. Cambridge; New York: Cambridge University Press.
19. Rawls, John. 1971. *A theory of justice*. Cambridge, Massachusetts: Belknap Press of Harvard University Press.
20. Watch Tower Bible and Tract Society. 1961. Blood, medicine and the law of god. Brooklyn, N.Y.: Watchtower Bible and Tract Society of New York.
21. MacDougall, D Robert. 2010. Rawls and the refusal of medical treatment to children. *Journal of Medicine and Philosophy* 35 (2):130-153.
22. Brummett, Abram. 2019. Whose harm? Which metaphysic? *Theoretical Medicine and Bioethics* 40 (1):43-61.
23. Grant, Kelly. The Globe and Mail. 2014. Ontario hospital cannot force chemo on 11-year-old native girl, court rules. 11/14/14. <http://www.theglobeandmail.com/life/health-and-fitness/health/cancer-patient-has-right-to-use-aboriginal-healing-instead-of-chemo-judge-rules/article21587859/> Accessed 9/22/18.
24. Walker, Connie. CBC. 2014. Makayla sault will not be apprehended by children's aid. 5/20/14. <https://www.cbc.ca/news/indigenous/makayla-sault-will-not-be-apprehended-by-children-s-aid-1.2648562> Accessed 9/22/18.
25. Hamilton Health Services Corporation v. D.H., P.L.J., Six Nations Of Grand River Child and Family Services Department and Brant Family and Children's Services (OntCtJ, C287/14E). <https://www.theglobeandmail.com/life/health-and-fitness/health/article21602507.ece/BINARY/Ms+JJ+Judgment.pdf>. Accessed 8/8/18.
26. Eggertson, Laura. 2015. Doctors should collaborate with traditional healers. *Canadian Medical Association Journal* 187 (5):E153-E154.
27. Guichon, Juliet, Ian Mitchell, Roxanne Goldade, and Victor Lew. The Hamilton Spectator. 2014. Makayla too young to make medical decision. May 31. <http://www.thespec.com/opinion-story/4550627-makayla-too-young-to-make-medical-decision/> Accessed
28. Schafer, Arthur. CBC News. 2014. First nations children not well served by chemotherapy ruling. Nov 20. <http://www.cbc.ca/news/aboriginal/first-nations-children-not-well-served-by-chemotherapy-ruling-arthur-schafer-1.2836141> Accessed

29. Walker, Connie. CBC News. 2014. First nations girl chooses traditional medicine over chemo. May 16. <http://www.cbc.ca/news/aboriginal/first-nations-girl-chooses-traditional-medicine-over-chemo-1.2644637> Accessed
30. Truth and Reconciliation Commission of Canada. 2015. *Canada's residential schools: The legacy*. Montreal: McGill-Queen's University Press.
31. Schwartz, Daniel. CBC News. 2015. Truth and reconciliation commission: By the numbers. June 2. <https://www.cbc.ca/news/indigenous/truth-and-reconciliation-commission-by-the-numbers-1.3096185> Accessed
32. Galloway, Gloria. The Globe and Mail. 2014. Medical system told to examine why aboriginal parents distrust it. 11/20/14. <https://www.theglobeandmail.com/life/health-and-fitness/health/medical-system-told-to-examine-why-aboriginal-parents-distrust-it/article21686603/> Accessed 9/22/18.
33. Adelson, Naomi. 2005. The embodiment of inequity: Health disparities in aboriginal canada. *Canadian journal of public health Revue canadienne de santé publique* 96 Suppl 2:S45-61.
34. Health Canada. 2009. A statistical profile on the health of first nations in canada: Self-rated health and selected conditions, 2002 to 2005. http://www.hc-sc.gc.ca/fniah-spnia/alt_formats/pdf/pubs/aborig-autoch/2009-stats-profil-vol3/2009-stats-profil-vol3-eng.pdf. Accessed 9/22/18.
35. Blustein, J. 1983. On the doctrine of parens patriae: Fiduciary obligations and state power. *Criminal justice ethics* 2:39-47.
36. LaFollette, Hugh. 1980. Licensing parents. *Philosophy and Public Affairs* 9 (2):182-197.
37. LaFollette, Hugh. 2010. Licensing parents revisited. *Journal of Applied Philosophy* 27 (4):327-343.
38. Schoeman, F. 1985. Parental discretion and children's rights: Background and implications for medical decision-making. *The Journal of Medicine and Philosophy* 10 (1):45-61.
39. Damico, Alfonso J. 1997. What's wrong with liberal perfectionism? *Polity* 29 (3):397-420.
40. Rawls, John. 2005. *Political liberalism*. New York: Columbia Univ. Press.
41. Mill, John Stuart. 1956. *On liberty*. New York: Liberal Arts Press.