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# When Parents Refuse: Resolving Entrenched Disagreements Between Parents and Clinicians in Situations of Uncertainty and Complexity

**Janine Penfield Winters**, University of Otago Bioethics Centre and Otago Community Hospice

When shared decision making breaks down and parents and medical providers have developed entrenched and conflicting views, ethical frameworks are needed to find a way forward. This article reviews the evolution of thought about the best interest standard and then discusses the advantages of the harm principle (HP) and the zone of parental discretion (ZPD). Applying these frameworks to parental refusals in situations of complexity and uncertainty presents challenges that necessitate concrete substeps to analyze the big picture and identify key questions. I outline and defend a new decision-making tool that includes three parts: identifying the nature of the disagreement, checklists for key elements of the HP and ZPD, and a “think list” of specific questions designed to enhance use of the HP and ZPD in clinical decision making. These tools together will assist those embroiled in complex disagreements to disentangle the issues to find a path to resolution.

**Keywords:** children and families; decision making; parental refusals; pediatrics; risk/benefit analysis

Disagreements between parents and medical providers about proposed treatments can usually be avoided or reconciled via thoughtful communication. Parents may refuse promising treatments because of concerns about uncomfortable side effects, risks of therapy, or other factors. Disagreements about how to prioritize potential goods and weigh potential burdens continue in clinical pediatrics. Particularly troublesome are disagreements about therapies that have long duration, require parent compliance, are not curative, or have uncertain outcomes. When shared decision making breaks down and parents and medical providers develop entrenched and conflicting views, an ethical or sometimes judicial framework is needed to find a way forward.

There are several existing frameworks that clinicians, ethics committees, mediators, and arbiters use to resolve entrenched disagreements for children too young to participate in decision making. In the first part of this article I briefly review the evolution of these frameworks and discuss advantages of the harm principle (HP) and the zone of parental discretion (ZPD). I consider how the HP

and the ZPD frameworks apply to clinical situations of great complexity and uncertainty. In the second part, I review the pitfalls in decision making for these types of cases. I identify the need for a tool to supplement ethical frameworks in order to break down the big picture into manageable clinical questions.

In the third part, I outline and defend a tool with three functions. The first function is an exploration into the nature of the disagreement. The second part harnesses the key elements of the HP and ZPD into two checklists. The third function is a “think list” of specific questions that will enhance the use of ethical frameworks to assist professionals charged with resolving the dispute to consider the variables involved in overruling parents in clinical situations of complexity and uncertainty. This tool is designed to reduce three common types of errors in approaching these decisions: reductionism, bias, and errors of omission. This decision-making tool can be considered a stepladder by which those embroiled in complex disagreements can disentangle the issues and ultimately find a path to resolution.

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## PART 1: FRAMEWORKS

When parents and clinicians do not agree about the treatment of an ill child, there is a dilemma of how to move forward. Ethical frameworks provide a supporting structure for clinical and legal professionals charged with the task of determining when to override parents as surrogate decision makers for their children.

A “framework” is defined as “a basic structure underlying a system, concept or text” and “an essential supporting structure of a building, vehicle or object” (*Oxford English Dictionary*). The physical meaning sets up a metaphor that I use to describe the new tool presented as a “stepladder,” to assist the user to reach the peaks of the framework. In practical terms, ethical frameworks assist decision makers to step back from any interpersonal aspects of a clinical disagreement and focus on the supporting structure for the differing positions.

In countries with well-developed child protection systems, the use of state powers to overrule is based on *parens patriae*. The state may act as surrogate decision maker when necessary to protect the life and health of those who do not have decision-making capacity (Diekema 2004). Overriding parents’ decisions for their child requires identifying and balancing specific harms and benefits in order to respond to the broad picture. Exacting distinctions are required, especially in situations where clinical uncertainty is high, the weighing of harms and benefits is influenced by differing values, and the potential for unintended consequences is difficult to foresee.

### Best Interest

During the 20th century, ethicists and courts had widely adopted the best interest standard (BIS) to determine when to apply *parens patriae* to medical decision-making disagreements. This standard was initially used in family law to resolve disputes between parents, and for decisions regarding foster care/adoption, child support issues, and custody determinations following divorce (Diekema 2011). In an interparental dispute, the arbitrator works with options put forward by the parents and attempts to either find a compromise or choose what is best for the child from the parent-provided options. Resolving clinician–parental disputes requires a different methodology because this type of dispute has many possible approaches to what is “best,” including values generated by someone outside of the family and culture. Adjudication of the absolute “best” is appropriate when choosing within options generated by the parents.

The idea that dispute resolution is based on determining and acting on the single best option for the child is immensely intuitively appealing, but when examined more closely, the BIS has serious flaws when applied to disagreements between parents and medical providers (Salter 2012). I discuss five limitations or flaws of the BIS

to demonstrate why the quest for more helpful frameworks is still an active area of ethical debate.

The first issue is that the BIS asserts there is “one best answer.” Difficult cases, however, require consideration of multiple options, multiple interests, and multiple value systems. A variety of perspectives on weighing and balancing “competing goods” in any given clinical situation often means that there is more than one “good” that is ethically justifiable. Salter’s review on this topic (Salter 2012) presents a case in which opposing viewpoints about experimental treatment for a child are both argued as in the child’s best interests. Salter states, “Because there are so many reasonable interpretations of what constitutes the best interest of a child, it functions merely as an empty, although sometimes alluring, catchphrase” (Salter 2012, 190).

Three examples of complex situations illustrate the difficulties of utilizing the BIS and the need for structured approaches in mediating dispute resolution. The first example is that BIS cannot determine a single “best” interest in the end-of-life setting (Baines 2008; de Vos et al. 2014; Gillam and Sullivan 2011). This is because there are unanswerable moral dilemmas when the only choices are within the constraint of late-stage noncurable illness, where prolonging life may cause suffering for the child. Reasonable people cannot come to consensus on when death is a better option for a child than prolonging a painful or unaware existence.

A second example is determining what is “best” in decision making about surgery for newborns born with hypoplastic left heart syndrome, a condition in which there is only one heart ventricle instead of two. In the past, infants born with this congenital heart defect had a dismal prognosis (Siffel et al. 2015). Treatment has improved in recent decades, but treatment requires a series of high-risk surgeries in the first year of life. With the surgeries, the infant has 50–60% chance of survival to age 1 year (Hirsch et al. 2011; Rogers et al. 2017). After age 1 year, the children usually do well throughout childhood. Thus, the surgical procedures are effective in palliating this serious cardiac anomaly but are also risky (some are left with serious permanent noncardiac disability), grueling (multiple invasive treatments), and expensive (Dean et al. 2011). The long-term outlook is still unknown, but serious sequelae, such as liver disease (Baek et al. 2010, Rychik et al. 2012) often present in early adulthood and there is a high risk of premature death in adulthood (Greutmann et al. 2015; Pundi et al. 2015). So, when are the potential beneficial results of this surgery compelling enough to consider overruling parents who refuse surgery? Doctors disagree (Feudtner 2008; Prsa et al. 2010; Kon 2008; Wernovsky 2008).

A final example, a case from my experience (with permission), is treatment refusal for an arteriovenous fistula found incidentally on brain magnetic resonance imaging (MRI) of an 8-year-old child. This type of vascular anomaly can lead to aneurism, bleeding, stroke,

and death, but the treatments are relatively new and also have risk. The parents were well informed about the condition and the risks. The parents refused recommended treatments, stating the risks were too high. They said they could cope with their child dying a natural death, but could not live with themselves if they chose the recommended intervention and the child had a severe complication, such as stroke or death, due to the procedure. Is there a single “best” answer? When are risks “too high,” and whose values should prevail?

These cases illustrate that literal interpretation of “best” interest does not reflect the way parents make decisions, either in everyday life or in high-stakes situations. Every day, parents choose options that they perceive as good for their family, but these choices are often not in the single “best” interest of a specific child. Most of these are low-stakes situations, such as transporting the child in a car or choosing less than optimal foods (Diekema 2004). However, higher stakes family decisions, such as moving, divorce, or financial decisions, may negatively affect a child and can be viewed as not in the child’s best interest. If courts were to review parental decisions based on the BIS for a specific child, then most parents would have a significant proportion of their life choices and decisions reversed.

A related difficulty is that the BIS does not acknowledge that children live in families and the child’s interests are “intertwined with the interests of others” (Lantos 1999). The BIS does not allow parents to consider the interests of the child as a member of a family (Blustein 2012; Diekema 2004; Ross 1998). The phrase “When Momma ain’t happy, nobody’s happy” is a folk saying that reflects the reality that parents cannot meet the needs of their children if their own needs are not met.

The next difficulty with the BIS is that it is usually applied narrowly to the biomedical interests of the child and not to the well-being of the child as a whole (Bowyer 2016; Diekema 2004). Emotional, social, and spiritual well-being are difficult to quantify and highly value-laden (Gillam 2016). Reasonable people can disagree on the values of the child petting the family dog, playing, or having “quality time” at home. These activities can have great meaning for children and families (Behrman and Field 2003). For children with life-limiting conditions, the American Academy of Pediatrics Committee on Bioethics states, “The goal is to add life to the child’s years, not simply years to the child’s life” (Committee on Bioethics 2000, 353). “Adding life to a child’s years” is difficult to adjudicate when parents and medical providers have different values about what qualifies as “adding life.”

A final difficulty of the BIS is that it does not specifically address the harms of overriding parental decisions (McDougall et al. 2016), and thus these consequences are easily overlooked. Most of the harms occur directly to the child and can be mild or severe. Harm to the parents

can result in a decreased ability to be supportive of the child’s needs while undergoing mandated treatments (Richards and Okninski 2017). One example of potentially extreme harm, although admittedly rare, is when parents flee or hide with their seriously ill child (Brandon 2001, Hord et al. 2006). In this scenario, the child and family lose all medical care, including management of troublesome symptoms. The parents and siblings may also lose the family’s support network and financial security.

Harms of overriding parents can extend far beyond the particular child and family. The unintended consequence of mandating treatment for one child is that it can impact other people in the community in which that child and family resides. Specifically, and importantly, if the community agrees with the parents about the particular decision and the values that underlie the decision, the act of compelling the treatment can erode community trust in the medical system. People from subcommunities with nonmainstream values may also lose trust in medical providers, and parents may refrain from seeking appropriate and timely medical interventions for their children (Gray and Gillet 2014; O’Neill 2002; Segraves 2015).

### Harm Principle

The harm principle (HP), as proposed by Diekema in 2004, seems much more synchronous with actual community standards and practices in decision making for children. The HP allows for “good enough” parenting (Hogughi and Speight 1998; Winnicott 1965) by not requiring a single “best” answer to “maximally promote” the well-being of the child (Wilkinson 2013; Wilkinson and Nair 2015). The HP is also more consistent with minimizing legal limitations on personal freedoms. In a liberal democracy, the individual is free to choose from a wide range of actions as long as they do not harm others (Haidt 2012; Mill 1966).

Diekema (2004) describes eight basic criteria of the HP. The first is that the refusal of the proposed intervention must put the child at significant risk of imminent harm which requires immediate action. The second criterion is that the intervention proposed must be necessary and efficacious in preventing the harm and not place the child at risk of serious harm. The burdens most not outweigh the benefits and there must not be a less intrusive option. Diekema clarifies that state intervention to overrule parents should generalizable to all other similar situations. Finally, the last criterion of the HP is a community test that “most parents” would agree that state intervention is reasonable (Diekema 2004).

The HP assists arbitrators but does not clarify all pediatric decision making. The most problematic issue with the HP is that the determination of significant harm is still difficult and dependent on values. Differing and competing values of parents, clinicians, and arbiters play

a role in disagreements about determining what constitutes harm (Birchley 2016; Sawicki 2016). The HP provides a better tolerance of variation in values than the BIS because the scope of decision “is this harmful?” is less stringent than “is this best?”

The HP is being adopted by ethicists as a preferred framework. A 2016 literature review delineated several ethical frameworks, including the BIS and the HP, that have been used to determine when it is justifiable to override parental decision making (McDougall and Notini 2014). While the debate is ongoing in this area (Birchley 2016; McDougall 2016; Wilkinson and Nair 2015), the review concludes, “There is substantial consensus among ethicists that harm is the central moral concept when judging the appropriate threshold for state intervention in parental decision-making” (McDougall and Notini 2014, 452).

### Zone of Parental Discretion

The zone of parental discretion (ZPD) is a recent contribution to the body of frameworks available for resolving parental–clinical disputes, but it has already become well recognized and used in academic presentations (Shnorhavorian 2017). The ZPD is defined by Gillam (2016) as the “ethically protected space where parents may legitimately make decisions for their children even if the decisions are sub-optimal for those children (i.e. not absolutely the best for them)” (Gillam 2016, 2).

The ZPD specifically prompts clinicians to include two items in the decision-making calculus that are not considered in the BIS and are only implied by the HP. The first item is the specific acknowledgment that there is a range (or zone) of decisions that are ethically acceptable. The second item is that ZPD prompts decision makers to explicitly acknowledge that overriding parents may create harms. In the worst cases, the relationship with parents and child is severed, the child foregoes all palliation and treatment, the family is traumatized, and a wider trust in the medical providers is undermined. Use of the ZPD is intended to improve the accuracy of benefit–burden analysis by including in the analysis the anticipated harm caused by overruling parents (Gillam 2016; McDougall et al. 2016).

The ZPD draws specific, systematic attention to the “morally significant gap” (Gillam 2016, 2) between what is optimal for the child and what will cause harm for the child. It “accords moral weight to the parents as the decision-makers for the child, weight which is often not properly taken into account when using the best interest test” (Gillam 2016, 2). Application of the ZPD results then in an “acceptable zone” in which parents are allowed discretion, even if some consider the choice sub-optimal. This is consistent with the concept of “good enough” parenting, initially theorized as the “good enough mother” in 1965 by Winnicott and subsequently described and widely discussed in multiple disciplines

including psychiatry, education, and child welfare (Winnicott 1965). “It is unhelpful and unrealistic to demand perfection of parents, and to do so undermines the efforts of the vast majority of parents who are in all practical respects ‘good enough’ to meet their children’s needs” (Hoghugh and Speight 1998, 293). Because the “good enough parenting” concept has been extensively explored internationally over the past half century (Hoghugh and Speight 1998; Ramaekers and Suissa 2011; Tregeagle et al. 1997), it seems a solid foundation upon which to build the ZPD. With the advent of family-centered care, there is greater acknowledgment that the child exists in a family and stressors and harm to members of the family (including siblings) stress the sick child.

Adding the ZPD onto the theoretical foundation provided by the HP strengthens the power and accuracy and also widens the applicability. Diekema confines the HP to the narrow scenario of involvement of the coercive powers of the state. The ZPD widens the scope of applicability and is thus relevant to other ways that health care providers can influence, coerce, or override parents. The ZPD is also described as a tool to assist in implementation of the HP (Gillam 2016). The framework recommends weighing several considerations; these are listed as part of Figure 1. A criticism of the ZPD is that it still necessitates determination of what constitutes “significant harm” or “good enough.” This is, once again, dependent upon values (Birchley 2016; McDougall et al. 2016).

### PART 2: PURPOSE AND DEVELOPMENT OF THE TOOL—AVOIDING MISSTEPS AND PITFALLS

The development of this tool is primarily the result of my experiences as a clinician and a member of a clinical ethics committee (CEC). I have participated in many CEC discussions about parental decisions for children and, over a period of years, noticed patterns. Specifically, I have noted variability in recommendations about overruling parents depending on who presented the case to the committee and what disciplines and personalities were present at any particular meeting. I have reflected on my experience and the writings of ethicists to categorize some of the types of missteps that arbiters might make in the decision to overrule parents. These include errors of omission, a tendency to try to reduce complexity, and inadvertent bias, particularly cultural bias toward medical culture and medical values.

#### Bias

The first pitfall is inadvertent bias. Bias is defined as “to give a one-sided tendency ... to incline to one side; to influence ... often unduly or unfairly” (*Oxford English Dictionary*). Biases due to cognitive errors are known to occur regularly in medical decision making (Croskerry



**Overview:**

1. What is the problem?
  - a. Is there an agreed understanding of the problem?
  - b. What are the parent's goals?
2. What are the proposed treatments or treatment?
  - a. Is there an agreed understanding of the treatment efficacy and side effects?
  - b. What are the parent's objections to treatment?
3. What is the length of the proposed treatment?
  - a. What is the level of uncertainty of outcome?
4. Are there any compromise treatment options?
  - a. Is it possible to take a step and then reevaluate?
5. Are there special circumstances?
  - a. Does the child have a separate life-limiting condition that influences decision making about this treatment?
6. What type of persuasion/coercion is under discussion?
  - a. What measures would be needed to implement treatment against parental wishes?

Harm Principle Checklist	
1.	Serious harm test: Refusal of proposed treatment leads to risk of serious harm.
2.	Immediacy test: That harm is imminent.
3.	Necessity test: Proposed treatment is necessary to prevent harm.
4.	Efficacy test: Proposed treatment has proven efficacy.
5.	Burden to benefit test: Burden–benefit ratio of proposed is significantly favorable.
6.	Compromise test: There are no other options for preventing harm that are acceptable.
7.	Generalizable test: Overriding parents in similar situations is acceptable.
8.	Reasonable parent/public scrutiny test: Most agree that state intervention is reasonable.
Zone of Parental Discretion Checklist	
1.	What are the effects to the child of the parents' preference?
2.	Are the effects so bad they constitute probable significant harm?
3.	What are the effects on the child if the medical providers resist or override the parents' decision? Could the negative effects be greater than the positive (or hoped-for) effects?

Special Circumstances (Narrative):

Balancing Burdens and Potential Harms (use Table 1):

Recommendations:

**Figure 1.** Decision-making tool for resolving disagreements between parents and clinicians when complex or long-duration treatments are refused.

2002). The many types of bias are too lengthy to review in this article, but value bias, visceral bias, and cultural bias are discussed because they are related to the need for frameworks in adjudicating parental refusals.

Value bias “refers to the tendency of people to express a stronger likelihood for what they hope will (or will not) happen ... We tend to believe that positively valued events are more likely to happen than negatively valued events” (Croskerry 2002, 1193). An example of values bias is, in adjudication of refusal of continuation of cancer care, parents may cite devastating side effects as part of their reasoning, while clinicians focus on the hoped-for result (Gray 2017; Richards and Okninski 2017). This idea is discussed further in the category of reductionism.

Visceral bias is another bias that can affect decision-making accuracy. Visceral bias is due to the feelings evoked in the providers and adjudicators about characteristics of the parents (Croskerry 2002, 1198). Visceral bias helps explain the observation that disagreements escalate when the health care providers feel uncomfortable with a family or experience the parents (and their values) as different or “difficult.”

Cultural bias has also been amply discussed in recent years. Gray states that “Given that culture is about values and beliefs it follows that what is ‘right’ is culture bound” (Gray 2017, 2). One well-known work describes the misunderstandings between an immigrant (Hmong) family and their health care providers (Fadiman 1998). These clinicians and the Hmong family were operating from very different cultural bases. The chasm between their different perspectives on what treatments were helpful to the child was not bridged.

I observe that adjudicators operate in at least three cultures: their professional subculture, their culture of origin, and the prevailing societal culture. The professional subcultures of medicine can vary from the general cultural, and thus values and goals may differ. Medical professionals are selected by academic ability and success. They are further molded by schooling, strenuous training, and long apprenticeships into “future-oriented” individuals (Zimbardo and Boyd 2015). This future focus, and “healer” roles, are noticeable examples of how health professional subculture diverges from the general culture.

Examples of culture influencing decision making are drawn from my experiences on CECs. In my experience, cases brought to the pediatric CEC were usually presented to the committee by medical providers, and the initial analysis was guided, or even dominated, by their question and agenda. The committee strived for completeness and excellence. Yet my health care peers and I were also influenced by the professional subculture. We relied on the presentations of the clinician to both introduce the case and describe the medical “facts” of the accompanying conflict. (The word facts is in quotes here because the information presented as facts usually

included interpretation and prognostication that were judgments presented as “facts”). Despite our intention to provide a balanced, family-centered approach, the “facts” as presented by one clinician and the accompanying arguments had a lot of weight. The members of the CEC generally knew, and had collegial regard and respect, for their medical peers. This influenced and medicalized our first impression of the cases. The members then tried to understand the family’s values, but these were often less clearly articulated as families speak from outside of the medical culture and vary in their skill to communicate. The focus of CEC discussions was primarily on medical interests and secondarily on the parental motivation in their disagreement with the recommended medical course. Even with sincere goals for family-centered care, the CEC was under an “umbrella” of a hospital system with professionals focused on medical values. In the setting of conflict between medical providers and parents, these medical goals often outweighed all other values, including social and psychological well-being.

### Errors of Omission

Professional arbiters can also make errors of omission. Two examples of these are underrecognition of rare but serious negative treatment results, and the omission of recognition of possible consequences of overriding the parents.

Medical advisors, in relaying the medical “facts” of the case to other arbiters, may unintentionally underemphasize or even omit the possibility of relatively rare but serious unintended effects of treatment such as the exposure to medical errors, permanent disabilities, suffering due to treatment, or even death from complications. One reason that serious negative results are mistakenly omitted from discussion is “value bias,” as described earlier. Value bias helps explain why such important negative effects are sometimes inadvertently overlooked from the decision-making calculus. The same “rare but serious” occurrences have great moral weight when the treatment is compelled against the parents’ wishes.

As previously discussed, users of the ZPD are specifically reminded to weigh the probable harms to the family and child that can occur from overriding parents. Some of these consequences were difficult to predict because long-term consequences were not captured by the medical literature. Recently, organization of clinical case reports documenting these unintended consequences has become available (Gray and Brunger 2017). A checklist-type tool is one effective method of minimizing errors of omission (Gawande 2011; Glasgow et al. 2016; Kim et al. 2015).

## Reductionism and Complexity

When a clinical situation is straightforward and treatment options are effective, immediately needed, and lifesaving, the decision to overrule parents is relatively routine in Western medicine. This is the case with lifesaving blood transfusions for children of parents who are of the Jehovah Witness faith (Committee on Bioethics 1997).

When treatments are high-risk or long-term, overriding parents becomes more problematic and it is almost impossible to predict all of the possible outcomes—intended and unintended. Long duration of treatment inevitably introduces variability. Many unexpected events can occur in the thousands of steps that need to be taken between the decision and the final date of completion of treatment.

In approaching the complex decisions, there is a tendency to attempt to simplify the criteria to one metric. For example, in cancer treatments, this one metric is the predicted survival with treatment (Brown and Slutzky 2017). Brown's review of refusals of childhood cancer treatments acknowledges that the single statistic of predicted percent survival was the main factor in decisions to overrule parents and compel treatment (Brown and Slutzky 2017). Reduction to one (postulated) number may help reduce anxiety due to overwhelming complexity but masks that clinicians can never know how odds apply to one particular patient. This review also describes "the significant variation in approaches and a lack of consensus regarding the prognostic threshold necessary for compelling treatment" (Brown and Slutzky 2017, 1). Parents who refuse cancer treatment do not seem to focus on the same information as their clinicians. For example, some parents seem to focus more on side effects and quality of life and less on prognosis. There is no current consensus about how to weight the estimated 25% occurrence of death from treatment itself for those who die during treatment of childhood cancers (Brown and Slutzky 2017). A recent report about refusal of child cancer treatment finds that the timing of refusal is most often after initiation of treatment when side effects have been observed (Gray 2017). Artificially reducing complexity in decision making decreases the appreciation what complications could occur during the treatment journey.

The job of the mediator or arbitrator involved in disputes about long-duration treatments would be assisted by a tool that breaks down the decision making into smaller and more manageable questions that can then be assembled into an overall framework. The intention of a "stepladder" tool is to assist the decision makers to come to the most complete and reasonable decision while avoiding reductionism, bias, and inadvertent omissions.

## Implementation of the HP and ZPD Into Clinical Practice

The recent addition of the ZPD to the HP widens the applicability, thus making it a framework that can be

used in many pediatric treatment disagreements. Despite robust discussion in the bioethics literature (which cannot be completely captured in this short review), and the documentation of an emerging consensus (McDougall and Notini 2014), the BIS continues to predominate in nonacademic settings rather than the models focused on harm (Salter 2012). In my experience in clinical pediatrics, the phrase "best interest of the child" is part of the day-to-day lexicon of clinicians, so awareness and probable adoption of the newer innovations will take time.

A recent example that describes the BIS being used as the sole framework in decision making is a 2016 case report that describes the rationale for the decision making in the first part of the *Kiszko* case in Western Australia (Okninski 2016). The parents were opposed to cancer treatment for their child, and Okninski explains that BIS was applied as the key argument for overruling parental refusal of cancer treatment, as "the court focuses on the child's best interests" (Okninski 2016, 365). The author applauds the BIS as the right tool for this job: "*Kiszko* affirms the well-established rule that the personal convictions of the parents are secondary to the best interests of a child" (Okninski 2016 368). The author continues that, "*Kiszko* affirms that the courts will not hesitate to exercise its *parens patriae* jurisdiction" and "The court also demonstrated a willingness to take the extra steps of curtailing the parents' freedom of movement by ordering them to surrender their passports and remain at their current address" (Orkininski 2016, 368). This initial report was followed by a second paper with a more complex analysis and the *Kiszko* case went on to a broader decision-making calculus in later months (Richards and Okninski 2017). Then, the use of the BIS was tempered by other factors that were not able to be included in the time-sensitive first hearing.

In order to improve appropriate implementation, a clear method for practical use of the harm principle and ZPD needs to be further developed. A checklist type tool, as borrowed from the quality improvement literature, is one method to cue arbiters that there are alternatives to the BIS that may be more applicable to the parent-clinician disagreement.

## PART 3: WHY, WHO, WHEN, AND HOW TO USE THE TOOL

### Why

The proposed tool is intended to be helpful in improving communication, understanding the entrenched agreement, resolving the dilemma, and avoiding unanticipated negative consequences. Family culture has become more recognized and respected in the era of family-centered care, and this tool assists recognition of differing values as the underpinning of the disagreement. The tool is intended to assist arbitrators to avoid inadvertent (cultural) bias and the unintentional imposition of their



own values onto a family. In designing a tool with several purposes, I use a key idea from the quality improvement literature. This literature, popularized by Gawande, has robustly demonstrated that checklists work as tools to reduce errors (Gawande 2011). For pediatric decision making, a checklist will assist in reminding clinicians, ethicists, and judges to consider a wide range of factors. It cue arbiters to ask further questions, remember nonintuitive benefits and harms, anticipate potential sequelae, and attempt to avoid inadvertent omissions while weighing the options. It includes a “think list” of potential benefits and harms, rather than a checklist, as it does not include “check boxes” due to the just criticisms of checkbox fatigue resulting in less efficacy of checklists over time (Anthes 2015). Cases with high complexity and uncertainty make it difficult to determine whether parental choices fall with the criteria of the HP or the ZPD. While the ZPD and HP are excellent frameworks for discussion and decision making, they are not specific enough to guide arbiters through complex cases to a single decision.

While each situation is unique, guidance from clinical reports and court precedents would be ideal. It is challenging to learn from prior experience in this area as it is difficult to locate articles that report long-term outcomes and reports rarely capture longitudinal effects (of overriding parents) on the individual, the family, the arbiter, or the community. It remains notoriously difficult to overcome the challenge of remembering the forgotten. The tool is designed to assist in cueing arbiters to a systematic approach and to preemptively consider prior experiences with unintended consequences.

Some scenarios resulting from overriding parental decision making that this “think list” captures include:

- The parents become unable to care for the child after the required intervention.
- The required intervention requires daily in-home maintenance for a long period of time that must be enacted to achieve the desired outcome.
- The family life and parent-child bonds are so disrupted that the parents no longer attend to the child’s needs.
- The child suffers increased anxiety and pain during mandated treatments, because of decreased parental ability to be supportive of the child’s needs while undergoing mandated treatments (Richards and Okninski 2017).
- The child suffers physical or emotional harm because parental resistance to treatment leads to compulsion with restraints or sedation for compliance (i.e., requiring sedation of the child to ensure treatment when voluntary cooperation occurred if parents were supportive).
- The treatment exposes the child to events, such as a medical error, that cause serious (permanent) harm.
- The disputed treatment has unforeseen complications that cause harm, disability, or death.

- The family flees with or hides the child and forfeits all medical care.

### Who and When

This tool is for decisions for young children who cannot appreciate the medical condition and the decision under discussion. The tool can be adapted for use with the older child who has an awareness of the situation and values. The older child needs to be interviewed for his or her opinion and capacity for assent. The child’s voice then is recorded along with parental and clinician views. This tool is not complete for older children such as adolescents, and an additional section is in development. This supplement will attempt to capture the narrative of the older child, including the reasoning and values underlying congruence or noncongruence of their opinion with that of their parents. The potential for harm in overriding the parents is magnified when the older child’s opinion is firmly congruent with the parents’ view. Then the child’s lack of assent to medical intervention can escalate to refusal to cooperate, threatening to run away or self-harm. The supplement will screen for coercion or unbalanced influence from others. The older child supplement will attempt to weight the opinion of the child based on his or her understanding of medical information and the assessment of his or her developing capacity.

This tool cannot be applied to parental requests for treatment that the medical provider is ethically uncomfortable in delivering to the child. In most jurisdictions, a provider may refuse to execute nonbeneficial, futile, or harmful treatments, and decision making is based on resource allocation (cost threshold) as well the providers’ duty of nonmaleficence (Wilkinson and Nair 2015; Massie 2016).

### How to Use This Tool

The tool is envisioned as step in the decision-making process. One role of the tool is to assist arbiters to identify as many possibilities as can be imagined in a complex system. This tool is for the clinicians and arbitrators, while the parents are encouraged to use a tool with different structure, such as the Seattle Decision Making Tool (Hays et al. 2006; Pediatric Advanced Care Team, Seattle Children’s Hospital). After utilization of both tools, areas of agreement have been identified, areas of disagreement are explicit, values underlying the disagreement articulated, and all opportunities to bring the parties together without a binary (win-lose) setup have been explored.

The tool is designed to help break down a highly complex decision into manageable pieces. It begins by cueing the users to clarify the problem and identify standard and novel options. The “lack of mutual understanding” (Spinetta et al. 2002, 114) is a hallmark of a

**Table 1. Think list for balancing potential benefits and potential harms of proceeding with treatment despite parental opposition.**

Likelihood rating: V = very likely; S = somewhat likely; N = not likely; U = unknown/uncertain or need more information	Rate
Green light—Factors supporting the proposed treatment. Likelihood that treatment would:	
<ol style="list-style-type: none"> <li>1. Result in complete cure (without ongoing consequences or treatments)</li> <li>2. Meet goals of the               <ul style="list-style-type: none"> <li>-Treatment team</li> <li>-Family</li> </ul> </li> <li>3. Reduce or eliminate unpleasant symptoms               <ul style="list-style-type: none"> <li>-Short term</li> <li>-Long term</li> </ul> </li> <li>4. Improve the child’s ability to enjoy activities of childhood</li> <li>5. Improve child’s ability to participate in home and family life</li> </ol>	
Other benefits (list):	
Red light—Unacceptably bad sequelae of proposed treatment	
<ol style="list-style-type: none"> <li>1. Treatment itself could result in death or serious permanent disability (suggested threshold &gt;1 in 200, dialogue on threshold encouraged)</li> <li>2. Complications from treatment could result in death or serious permanent disability (anesthesia, surgery, sepsis, clot, stroke, bleeding, errors etc.) (suggested threshold &gt;1 in 100, dialogue on threshold encouraged)</li> <li>3. The proposed treatment is newly incorporated, unproven, or likely to change</li> <li>4. Permanent separation of child from family due to this treatment</li> <li>5. Overriding parents may result in serious setback to child’s interests (family flees) or unusual risks (delays, restraints)</li> </ol>	
Orange light—Likelihood of serious drawbacks or burdens	
<ol style="list-style-type: none"> <li>1. Extended treatment duration or more than one episode of care</li> <li>2. Relapse or re-occurrence expected</li> <li>3. Pain, symptoms, or suffering due to treatment               <ul style="list-style-type: none"> <li>-Weight by severity</li> <li>-Weight by duration</li> </ul> </li> <li>4. Other burdens to child               <ul style="list-style-type: none"> <li>-During treatment</li> <li>-After treatment, include disability</li> </ul> </li> <li>5. Requires parents to participate in treatment on an ongoing basis, including care for implanted device, or lifelong treatment requiring active family participation</li> </ol>	
Yellow light—Caution	
<ol style="list-style-type: none"> <li>1. Separation of child from home environment for more than one short episode</li> <li>2. Likelihood of serious burdens to parents/siblings due to treatment</li> <li>3. Overriding parents expected to have negative impact on the child, siblings, and family stability</li> <li>4. Overriding parents has negative impact on a subculture or community in which the child resides (loss of trust leads to decreased access by community)</li> <li>5. Treatment proposed not available in family’s subculture and cannot be continued once family returns to their home culture (e.g., international visitors)</li> </ol>	

parental decision to refuse recommended treatment. The tool can assist the arbitrator to understand the basis of the opposing views and bring the parties closer to mutual understanding and then find a way forward. The list portion of the tool is intended to minimize missteps and unexpected consequences by elucidating and articulating them early in the decision-making process.

The first section of the tool prompts the user to clarify the dispute and what each party wants (Figure 1). Then the user proceeds to the “think list” prompts, which are color coded to assist in assigning a weight to the concern queried (Table 1). The “green light” list

prompts the users to outline the goals of treatment and the intended good. The red, orange, and yellow light lists prompt for potential disadvantages or harms associated with overriding the parents. The most serious questions are in the “red light” list, which includes the more deeply troubling scenarios, such as the possibility that the mandated treatment itself causes the child’s death.

The “think list” is meant to be flexible enough to be applicable to multiple types of refusal scenarios, from surgical interventions to invasive testing, from cancer treatments to seizure treatments, and from lifesaving

treatments to symptom management disputes at the end of life. It is acknowledged that any list cannot cover all circumstances, so it also includes prompts for special circumstances and narrative to enhance and personalize analysis.

When the parties continue to be entrenched in conflicting views after full explorations are completed, the think list still functions as stepladder to the decision-making frameworks of the ZPD and the HP. The completed tool is an excellent record of thought processes that went into every aspect of the decision.

### COMPELLING NARRATIVES

While a decision-making tool can function as a “stepladder” to reach the frameworks described in the HP and the ZPD, there are some cases that still fall out of this approach due to complex unique circumstances. These are captured in the special circumstances narrative portion of this tool (Figure 1). Parental narratives are vitally important in pediatric cases because this narrative is part of the child’s reality and influences the child’s beliefs and thus the child’s suffering. Compelling narratives require extra time to consider and extra attempts at mediation to find solutions that are not win-lose for the different interests. Four examples of compelling narratives are described next. These are the end-of-life narrative, the previous child narrative, the cultural narrative, and the parent expert.

- The end-of-life narrative: Removing a child nearing the end of life from his or her parents and home can be described as a lose-lose scenario and seems repugnant and cruel. This scenario raises questions regarding if and when a life-limiting condition bestows more parental discretion to refuse proposed treatments.
- The previous child narrative: Some parents have made difficult decisions for another child and strongly wish to take a different course. The parents may specifically state, “We have done this before and want to avoid that future for this child.” Should they be forced to make the same decision again?
- The cultural narrative: Is it acceptable to mandate an intervention in this setting or culture that is completely inaccessible and unworkable in their home culture?
- The parent expert for a child with severe disability: Are parents of atypical or severely disabled children the experts on their child? Is the threshold to override parents of a child with severe disabilities any different than that of a typical child? Is there a different value to the child of remaining in the care of a loving family of origin when the child will never become independent in caring for herself?

These examples demonstrate why compelling narratives deserve special consideration even though they add to the complexity of decision making. By including a narrative section in the checklist, I have discarded one stated premise of the ZPD, which is that the individual reason for parental refusals is irrelevant (Gillam 2016; McDougall et al. 2016). Inclusion of the narrative is compliant with Diekema’s articulation of the HP because compelling narratives can sway community and public opinion.

### CONCLUSION

The tool proposed here aims to assist and prompt those charged with resolving disputes of factors that are not immediately obvious and thus potentially overlooked. The tool closely follows and includes the criteria of the harm principle and zone of parental discretion frameworks. The HP and the ZPD are excellent overarching frames, but a “stepladder” of more specific guidance is needed to avoid errors of bias and omission in determining the best course of action in a complex, high-stakes decision. The proposed tool supports the frameworks by cueing clinicians, mediators, and arbitrators to identify and weigh key factors.

This tool, like the ZPD, cues the user to reflect on the potential harm resulting from overriding parents.

A decision maker cannot imagine all the potential outcomes and unexpected consequences of overriding parents to compel long-duration or risky treatment for a child. In other words, anything can happen and it usually does. Case studies give anecdotal reports of unintended consequences of overriding parents. These published reports, however, are varied and not collected into a single, easily accessible body from which clinicians, ethicists, and judges can draw to learn from others’ experiences. This tool is used by arbitrators to attempt to capture as many variables as can be anticipated or gleaned from other’s experiences. The parents should be encouraged to complete a tool, such as the Seattle Decision Making tool (mentioned in the preceding), that assists in elucidating their values. Together, these tools provide structure to explore the facts and values underlying complex situations and, with the HP and ZPD, allow resolution of difficult decision-making dilemmas. While this tool is devised for long-term, complex or risky situations, it can also be helpful in improving mutual understanding in situations that are less complex. ■

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