the child against competing obligations. According to the **reasonable subject standard**, parents should decide for their child as the child would if she were a moral agent trying to act prudently within the constraints of morality (Millum 2018). Thus, in cases where other people’s interests are not at stake, the option that best promotes the child’s interests should be taken. In harder cases, such as in deciding whether to enrol a child into research, donate a kidney to a sibling, or give less attention to one child in order to give more to a child with greater needs, a balance must be struck. We strike that balance by considering what duties to others the child would have if she were a moral agent, including duties to claim no more than her fair share of societal resources, duties of beneficence to help others at low cost to herself, and familial duties to those with whom she has close relationships. We then select the option that is most in her interests while fulfilling those duties.

The reasonable subject standard adopts, as it were, a neutral perspective on the child’s interests. It therefore does not accept the parents’ religious beliefs as having any greater plausibility than anyone else’s. Thus, in assessing whether blood transfusion is in the child’s interests it considers only the effects for which there is evidence that a neutral party would accept. Considered this way, receiving a blood transfusion is in the child’s interests and refusing it is against the child’s interests. There is no need to assess the consistency or otherwise of the parents’ arguments. Since, we may assume, there are no competing obligations (we are not, for example, in a context where blood products are extremely scarce), the reasonable subject standard renders the sensible judgment that the blood transfusion should be given over the parents’ objections.

Bester is right that decisions for children are more complex than the harm principle would imply. He is also right that the standard parents use for proxy decision making must take into account other moral considerations in addition to the child’s interests. I reject only his framework for operationalizing his standard and recommend the reasonable subject standard as a workable alternative that I elaborate and defend elsewhere (Millum 2018, Chapter 6).

**DISCLAIMER**
The views expressed are the author’s own. They do not represent the position or policy of the National Institutes of Health, the U.S. Public Health Service, or the Department of Health and Human Services.

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**In Defense of Best Interests: When Parents and Clinicians Disagree**

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Cases where there has been entrenched disagreement between parents and clinicians have received a great deal of media and academic attention in the United Kingdom (UK) over recent months, with the agonizing stories of Charlie Gard and Alfie Evans exemplifying what can happen when parents and clinicians disagree about the best course of action for a child. While Winters’s proposed tool (Winters 2018) manages disagreements between clinicians and parents where parents refuse treatment, it is the cases where parents want to pursue a (particular) treatment for their child that clinicians do not feel is in the child’s best interests that have been amplified in the UK media.

The most recent UK example was the case of Alfie Evans, a young boy suffering from a severe neurodegenerative disorder. He spent much of his short life receiving intensive care treatment. His clinicians determined that
there was no treatment for his condition that would improve his life quality or extend his life in a meaningful way, and therefore redirection of care to a palliative approach was in his best interests; his parents did not agree. A protracted, highly publicized “battle” between the parents and clinicians ensued; anger, frustration, and fueling of public outrage were based on often-erroneous assumptions about the clinicians’ intentions. Tensions converged into rowdy and aggressive demonstrations outside the hospital, and threats of the hospital being stormed resulted in police intervention. This campaign appeared to be perpetuated by a strong social media crusade against clinicians, often supported by media headlines (Morrison 2018). The level of mistrust in clinicians and the unshakable belief that doctors were not offering Alfie a chance at life/the best treatment available appeared not to be amenable to reason. This case may lead some to consider that the concept of best interests is poorly understood and unhelpful, yet we believe there is mileage in it yet. The decision that palliative care was the best option for Alfie was based on the considered opinion that Alfie was probably suffering as a consequence of his ongoing life support and that “Alfie may still have some awareness of pain and discomfort and this should therefore be kept to an absolute minimum considering that he might still be able to ‘feel’ uncomfortable sensation” (Alder Hey NHS Trust v- Evans 2018). Ultimately, a Supreme Court judgment ruled that life support should be withdrawn, and Alfie Evans died in April 2018, aged 23 months.

In her article, Winters examines the usefulness of best interests, which she describes as “usually applied narrowly to the biomedical interests of the child,” and asserts that the concept “does not acknowledge that children live in families.” This is contrary to the UK notion of best interests for children, which is enshrined within both UK law and professional guidelines and is described as “balancing benefits and burdens (of whatever type) of treatments and outcomes, whilst considering the ascertainable wishes, beliefs and values and preferences of the child and their family, the cultural and religious views of the latter, the views of those providing care for the child and what choice is least restrictive of future options” (Larcher et al. 2015). The assessment of a child’s best interests, therefore, needs to consider these wider contextual factors, encompassing far more than just medical best interests, and includes the views of parents and, where appropriate, the child. This articulation of what best interests means does then consider the wider family—siblings, grandparents—as well as the cultural and sociological context in which the child is being raised. Winters also argues that the concept of best interests is unhelpful as it provides only a single answer; however, if the preceding definition is utilized appropriately, we believe a best interest decision will be case specific and defines a range of actions that might be appropriate.

The level of potential harm or suffering are central to a best interest decision in the UK, and parental decisions would not be overridden “unless the child is suffering or is likely to suffer significant harm” (Ashya King (a child) 2014). This inevitably raises the question as to what is considered suffering or significant harm, but can be, in some cases, reasonably obvious. Preventing suffering or prolonging a painful or unaware existence is widely considered central to best interests and contrary to Winter’s assertion that “reasonable people cannot come to consensus on when death is a better option for a child than prolonging a painful or unaware existence” (21). When a child is suffering—for example, is ventilated, requiring invasive procedures causing pain, with no hope of treatment to alleviate their underlying condition or give them a meaningful existence—doctors should stop treatment that contributes to this suffering and aim to alleviate it by redirecting to palliative care. This approach to balancing the child’s best interests and treatment options has recently been described as a craft: utilizing therapies that will help with life’s quality but not unnecessarily prolonging inevitable death (Wallis 2018). The level of harm or suffering that a clinician or the state is prepared to accept is central to best interest decisions, and in the UK this level is relatively high. To some extent, the resolution of disagreement, or avoiding the point of disagreement, could also be described as a craft. With each child’s situation being unique, disentangling the nuances and potential outcomes is very difficult, if not impossible, to whittle down to a tool or checklist, and we have discussed elsewhere the need to consider each situation individually where treatment appears to be of no overall benefit (Fenwick et al. 2018).

Best interest decisions are often difficult, but in recent years they have added layers of complexity as new technologies and treatments have been introduced. As a pediatric intensivist colleague recently commented: The means that we have to keep children alive sometimes outweigh the ability we have to treat or ameliorate the underlying condition. In the UK, one of these layers of complexity is the resource restriction incumbent on clinicians; there simply is not the capacity to fully address these issues in the clinical situation. A protected space for discussion and sharing the burden of these decisions—such as in a clinical ethics committee—becomes essential. A tool such as the “think list” that Winters proposes may well reduce the impetus for such wider discussion. When presenting to a clinical ethics committee information on cases where clinicians and parents disagree, for example, Winters describes how clinicians “unintentionally underemphasize or even omit the possibility of relatively rare but serious unintended effects of treatment,” and have a “tendency to attempt to simplify” information into a binary decision. We consider that conveying complex information and projections about very ill children, which can only be done after many years of training and experience, is difficult. However, we do not think that clinicians are inherently biased or bring their own agenda, as suggested by Winters. It is, of course, the role of the committee to challenge colleagues when they believe this to be the case. Furthermore, inherent to focusing on best interests as a clinician is honesty—
honesty with oneself and others. Following on from high-profile cases such as that of Alfie Evans, certain sections of the press and social media have appeared to imply a general mistrust in doctors and have portrayed them as having their own agenda in relation to determining outcomes for children. Maintaining an absolute focus on the child by considering the broadest view of best interests, accounting for that child’s unique clinical, familial, and cultural circumstances in such situations, may be the only way to counter this mistrust.

While the tool that Winters describes goes some way to helping clinicians consider the consequences of overriding parents’ decisions when they are declining an intervention, it does not address the more common presentation where parents desire a treatment for their child that clinicians think would be of no overall benefit or indeed would contribute to suffering or harm. These conflicts are not going to go away. It is our view that adopting the broadest view of best interests, being deeply honest as a clinician, and trying to understand the particular experiences, expectations, and nuances in each unique case is the best “think list” in situations where parents and families might disagree.

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The Best Interest Standard: An Exhaustive Guide for Medical Decision Making in Pediatrics?

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In his article, Bester (2018) criticizes the so-called “harm consensus” movement among a growing number of bioethicists and practitioners. He argues that the harm principle is unable to replace the best interest standard as a paradigm for guiding and limiting parental decision making. After reviewing the main ideas of Douglas Diekema, one of the main proponents of the harm principle paradigm, the author highlights some important normative and conceptual flaws in this approach. Bester rightly points out that the harm principle lacks proper moral grounding because although many writers refer to Mill’s work On Liberty, most of them do not readily embrace his utilitarian liberal vision. Furthermore, the Millian account was developed to promote healthy social relations between adult citizens and is thus not easily applicable for pediatric decision making. Finally, according to Bester the harm principle is not easier to apply than the best interest standard because both concepts suffer from conceptual ambiguity. Moreover, the harm principle risks being reductive because it gives the impression that harm avoidance is the prime moral obligation for parents and physicians and that there is no longer the need to engage in the complex exercise of weighing competing interests. Despite Bester’s rightful critique of the harm principle, similar normative and conceptual objections can be made against his own framework.

To overcome the shortcomings of the harm principle, the author reaffirms the “best interest” position as the most suitable standard for medical decision making for children. He grounds the approach in the four principles of Beauchamp and Childress (2001) and further fine-tunes it by providing a “reasonable argument” test that should help health care providers to decide when