Within the ZPD: focusing on harm and children’s interests

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Editors’ summary
Harm is a crucial concept in the ZPD framework. The concept of probable harm to the child forms the outer limit of the zone of parental discretion, marking the point where parents’ decisions should be overridden. This chapter focuses on defining and explaining the concept of harm, and the closely related concept of interests, specifically in relation to children. In short, harm is done to a child when she experiences a large setback to her interests. In explaining what might count as a large setback to interests, the authors set out various accounts of what children’s interests are in general, and suggest a possible list of children’s interests that are specific to healthcare. An assessment of harmfulness involves comparing the overall extent to which a child’s various interests are promoted or set back by the different possible options. The authors suggest that, in the end, this will always involve some degree of individual judgment. There is no straightforward formula to calculate whether a parental choice is likely to set back a child’s interests so much that it counts as harm to the child.

Links
See Chapter 10 for Kerruish and Snelling’s discussion of critical and experiential interests.

Doctors have long been guided by the mantra “first do no harm”. But what exactly does it mean to harm a child? How do we assess whether or not an outcome is harmful? The concept of probable harm to the child forms the outer limit of the zone of parental discretion; it is the harmfulness of the parent’s choice that determines whether or
not clinicians ought to accept it. Therefore we need to look in detail at the concept of harm to the child in order for the ZPD framework to be a useful tool in complex cases.

In this chapter, we focus on how to understand the concept of harm, through a discussion of harm and children’s interests. Harm relates to the idea of interests, even though there is an important difference between harming a child and failing to act in his or her best interests. In the first section, we put forward a definition of harm as a significant setback to interests, where significance is understood in terms of magnitude. In simple terms, we suggest that a child is harmed when she experiences a big setback to her interests. We then investigate various accounts of children’s interests in the second section, highlighting points of consensus and of controversy. In the third section, we consider what might constitute a significant setback to a child’s interests, that is a harm. We suggest that there is no straightforward formula for determining whether a parental choice is harmful, but that an assessment of harmfulness involves comparing the overall extent to which a child’s various interests are served by the different possible options.

Harm = significant setback to interests (Section 1)

Interests = components of wellbeing (Section 2)

Significant setback = big difference between child’s wellbeing in option A and child’s wellbeing in option B (Section 3)

1. Defining harm

The concept of harm can be defined and understood in a variety of ways. Its meaning in the healthcare context clearly includes not just physical harm, but also psychological and emotional harm (Beauchamp & Childress, 2001: 117). Harm to a child can come about through the actions or the inactions of others, whether or not they were intended to cause harm. All of these sorts of harm matter in an ethical sense. So the definition of harm used in the ZPD needs to work for all of these different types and sources of harm.
One influential definition of harm is that given by Joel Feinberg. Feinberg defines harm in terms of a setback to an individual’s interests. He defines the plural “interests” and the singular “interest” in the following related way:

One’s interests ... consist of all those things in which one has a stake, whereas one’s interest in the singular, one’s personal interest or self-interest, consists in the harmonious advancement of all one’s interests in the plural. These interests, or perhaps more accurately, the things these interests are in, are distinguishable components of a person’s wellbeing: he flourishes or languishes as they flourish or languish. (Feinberg, 1984: 34, italics in original)

An interest has been set back when it is left “in a worse condition than it would otherwise have been” (Feinberg, 1984: 34). We will use harm to refer to a setback to interests which is of a certain size. A setback to interests crosses the line and becomes a harm when it is significant, and we define significance in terms of magnitude. So, a setback to interests is a harm when the setback is “big enough”. We will discuss later in this chapter how to think about the idea of “big enough”, but for the moment, we simply state our definition of harm: a harm is a significant setback to interests.

With this definition of harm, there are two obvious questions to ask next in order to be able to effectively interpret the harm threshold involved in the zone of parental discretion. One is “what are children’s interests?”. The other is “how big does a setback need to be to count as significant?”. In the next section, we therefore explore in more detail what is actually meant by the term “interests”, and how we might conceptualise interests specifically in relation to children rather than adults. In the section after that, we address the threshold issue of what is a significant or big enough setback to interests to count as a harm.

2. What are children’s interests?

The concept of interests tends to be situated squarely within the realm of wellbeing. For example, Wilkinson states that “an individual’s interests together contribute to their wellbeing – how well or badly their life overall is going” (Wilkinson, 2013: 109). This echoes Feinberg’s discussion of interests, quoted above. It therefore
seems that there are two significant, interrelated issues at stake when considering the theoretical underpinnings of children’s interests. The first is how we should conceptualise children’s wellbeing in an overall or general sense. The second is how we might determine what the individual components of this general state of wellbeing may be – or put very simply, what items are on the list of the interests of the child?

*Children’s wellbeing overall*

Popular use of the term “wellbeing” usually relates to health, but the philosophical sense that we employ here is broader and relates to the notion of how well a person’s life is going for that person. A person’s wellbeing can further be described as what is non-instrumentally or ultimately good for them (Crisp, 2013). Articulating what underpins, or determines this state of wellbeing is a topic that has entertained philosophers for centuries. It has become standard to distinguish three different types of theories: hedonistic theories, desire-based theories and objective list theories. These are explained very briefly below. All three types were developed in relation to adults and have been critiqued in relation to how they may pertain to children, who are still developing in myriad ways including physically, psychologically and morally.

Classical hedonists such as Bentham consider that wellbeing is constituted by the presence of pleasure and the absence of pain in one’s life (Bentham, 1789). Although hedonism is often (unfairly) associated with negative connotations of self-indulgence and physical excess, not all versions of hedonism rely on notions of pleasure. One version of hedonism is premised on the idea that although some experiences may not be pleasurable, they are nevertheless enjoyable and/or satisfying and contribute to our life going well. For example, it is possible to enjoy and derive considerable satisfaction from climbing a mountain, even if the last difficult part of the ascent cannot be described as pleasurable (Crisp, 1997: 28). Such “mental statism” accounts, which “take the good to be the having of certain conscious states”, consider that enjoyment or satisfaction and an absence of suffering or distress are what makes a life good for the individual living it (Degrazia, 1995: 52). However, Degrazia cogently argues that a further condition should be imposed to provide a full account
of welfare on this approach. Using an example of an infant who is painlessly killed, Degrazia claims that even though the killing did not cause suffering or distress at the time, it still counts as a harm because it robs that infant of future opportunities for satisfaction or enjoyment (Degrazia, 1995: 53). Consequently, Degrazia argues that the mental statist account of welfare should not be dependent only on experiencing actual satisfaction or enjoyment, but also on retaining “opportunities for future satisfaction” (Degrazia, 1995: 53). One critique of mental statist in relation to children’s interests is that these theories, at least in their basic form, provide no basis for distinguishing between different types of satisfying or enjoyable experiences, some of which may ultimately be more valuable than others, in a developmental sense, for children (Binik, 2014: 7-8).

The second type of theory is desire-based. Desire-based theories hold that the good consists in the fulfilment of an individual’s preferences or desires. However, it is certainly true that some of our immediate, short-term desires may not be consistent with our overall long-term interests. For example, a child may want to consume a bottle of her grandmother’s pills, because she thinks they taste nice, but this clearly will not augment her welfare (Degrazia, 1995: 54). Consequently a comprehensive desire-based theory of welfare requires the satisfaction of a person’s desires over their life as a whole, which requires that one’s desires are rational and fully informed (Crisp, 1997: 55). Desire-based accounts are clearly problematic terrain for young children as although they have and can express desires, they cannot know and understand what is good for them. Given the impossibility of children fulfilling requirements for rationality and being fully informed, it is difficult to see how desire-based approaches can function effectively in childhood (Binik, 2014: 8 [citing Kraut, 2007]).

The third theory of wellbeing is objective list theory, which identifies certain core values or non-instrumental goods that are considered to constitute welfare, and should be instantiated in every individual’s life (Crisp, 1997: 58). Inclusion on an objective list depends upon “substantive claims about what goods, conditions, and opportunities make life better” in general (Scanlon, 1993: 189). One objective list formulated by legal scholar John Finnis posits seven “basic aspects of human wellbeing” (Finnis, 1980: 85). Philosopher
Martha Nussbaum has formulated an objective list of “capabilities” that are linked to wellbeing and are necessary for a minimally flourishing life (Nussbaum, 2011: 33). To illustrate the kinds of things that appear in objective list accounts, the following table maps the values or goods that each of these authors suggests are universally required to live a flourishing life.

Table 2: Examples of the components of objective list accounts of wellbeing

<table>
<thead>
<tr>
<th>Finnis: core values</th>
<th>Nussbaum: capabilities approach</th>
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</thead>
<tbody>
<tr>
<td>Life</td>
<td>Life</td>
</tr>
<tr>
<td></td>
<td>Bodily health</td>
</tr>
<tr>
<td></td>
<td>Bodily integrity</td>
</tr>
<tr>
<td>Knowledge</td>
<td></td>
</tr>
<tr>
<td>Play</td>
<td>Play</td>
</tr>
<tr>
<td>Aesthetic experience</td>
<td>Senses, imagination and thought</td>
</tr>
<tr>
<td>Sociability (friendship)</td>
<td>Emotions: being able to have attachments to other things/people</td>
</tr>
<tr>
<td>Practical reasonableness</td>
<td>Practical reason; being able to form a conception about the good and engage in critical reflection</td>
</tr>
<tr>
<td>Religion</td>
<td>Affiliation; self-respect and equality</td>
</tr>
<tr>
<td>Control over one's environment (political status)</td>
<td>Other species</td>
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Objective lists have usually been constructed in relation to adults rather than children and thus many of the elements included do not represent children’s interests well (Binik, 2014: 8).

The criticisms of hedonism and desire-based theories (in relation to children) focus on the intrinsic nature of the accounts; in other words, the fundamental building blocks of each approach seem ill-suited to a comprehensive description of children’s interests. Binik has suggested that, in contrast, the criticism of objective list theories highlights problems with what may be included on the list rather than the very idea of constructing such an account in the first place.
(Binik, 2014: 7). She also argues that there are positive reasons for suggesting that the objective list approach may represent the most plausible existing way of conceiving of child wellbeing; given that it is widely considered appropriate for parents to make decisions on behalf of young children, it follows that we should probably be able to articulate what things are good or bad for a child irrespective of whether the child desires them (without necessarily disregarding a child’s likes and dislikes altogether) (Binik, 2014: 8). Objective lists also represent the standard view in healthcare, underpinning most quality of life measures (eg Child Public Health, 2011). Objective lists may perhaps be more clearly described as “universal lists” as they encompass both subjectively experienced elements and objectively observable elements.

Components of children’s wellbeing

There have recently been some attempts to construct more child-centric versions of objective lists. For example, Malek has constructed an extensive account of children’s essential human goods based on three sources: an account articulated by specialist clinicians, Nussbaum’s list of capabilities for adults, and the rights protected by the United Nations Convention on the Rights of the Child. Malek (2009: 2) argues that the overlapping consensus between these three accounts provides some evidence that the goods she describes form a comprehensive list of children’s interests. This extensive account has been distilled into a more manageable list of “seven substantive goods of childhood” by Binik, in the context of assessing risks to children involved in research (Binik, 2014: 9). Binik explicitly states that her:

proposal is not a comprehensive account of what it means to fare well for a child ... [but rather] an account of the substantive goods of childhood that ensure that a child fares well enough for her daily risks to be permissible in the context of nontherapeutic research procedures. (Binik, 2014: 10)

However, Binik’s description provides a useful summary of key points of consensus about children’s interests. Binik posits that children fare well when they possess sufficiently high degrees of all of the seven substantive goods summarised in Table 3 (Binik, 2014: 9-10, see over).
Table 3: Binik’s account of the seven substantive goods of childhood (Binik, 2014: 9-10)

<table>
<thead>
<tr>
<th>Substantive good of childhood</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>“A child must be in reasonably good health”</td>
<td>“the absence of diseases, disorders, or conditions that significantly impair (or whose medical treatment significantly impairs) normal functioning”</td>
</tr>
<tr>
<td>“A child’s biological needs must be met”</td>
<td>“sufficient food, water, sleep, and a safe home”</td>
</tr>
<tr>
<td>“A child must be provided with intellectually engaging activities”</td>
<td>“activities that challenge a child’s capacities ... (eg) playing with infants, reading to very young children, and formal education for older children”</td>
</tr>
<tr>
<td>“A child must be involved in meaningful relationships”</td>
<td>“loving attention from caregivers or guardians (ie parents or their equivalent)”</td>
</tr>
<tr>
<td>“A child must be able to enjoy unstructured, imaginative play”</td>
<td>“includes playing outdoors, laughing, and enjoying life”</td>
</tr>
<tr>
<td>“A child must have bodily integrity”</td>
<td>“her ability to be safe from assault, including sexual assault and domestic violence”</td>
</tr>
<tr>
<td>“A child must be happy”</td>
<td>finding life “enriching or rewarding, or feeling satisfied or fulfilled by it”</td>
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Binik’s list highlights some important points of consensus about children’s interests, and provides a plausible starting point. Clearly, the next question is how to weigh and balance the various interests. A list of interests, in and of itself, does not provide direction as to how the list should be put into practice. As Malek has argued, some explanation of how individual interests work together to determine a child’s overall wellbeing is needed (Malek, 2009). As Salter’s work has highlighted, accounts could vary significantly with regard to the types of interests they emphasise and prioritise:

- physiological (or somatic)
- psychological-emotional (affective states)
- relational (interpersonal connections or relationships such as bonds with family members)
cognitive-developmental interests (developing cognitive capacities, knowledge and skills). (Salter, 2012: 188)

In children's healthcare, the focus has gradually shifted from the physical or physiological towards a greater appreciation of the other types of interests. For example, the issue of an expanded conception of benefit (to include not just immediate medical benefit to the child but also benefits to the family such as information to inform future reproductive decisions) has been extensively debated in newborn screening (Bailey, Beskow, Davis et al, 2006: 270), and the treatment of children with disorders of sex development (DSDs) now focuses more on overall wellbeing than on the early surgical creation of unambiguous external genitalia (Gillam, 2015: 9).

Thus, children’s interests remain both agreed and disputed. There is currently no single comprehensive, practically applicable account. Indeed, it may ultimately prove impossible to develop one unified account given the different conceptions or weighting of interests we may have at different developmental stages. However, in the literature overall, there is some agreement on a general account of children's broad interests.

It seems that different degrees of specificity about interests will be needed in different contexts. For example, in the paediatric healthcare context, an interest in “good health” needs to be specified in far greater detail to be useful. We suggest that a list of children's interests in the paediatric healthcare context needs to include at least the following:

- being free from pain
- having good physiological function
- having the maximum possible lifespan
- being happy
- having bodily integrity
- being able to play
- living at home
- attending school
- having meaningful relationships.

In some cases, conflicts between parents and clinicians will arise because they have different fundamental ideas about what makes a child's life go well. But more commonly, people will have the same
fundamental idea, yet disagree about whether one individual interest is more important than another, or how much impact there will be on a particular interest in a specific situation. An important step in thinking about these more common disagreements is to try to establish an account of how much setback to interests constitutes a harm, because that is the question that is central to using the ZPD.

3. How much setback to interests counts as significant?

A child’s overall interests are made up of a number of distinguishable individual interests, as we have described above. This is represented visually in Figure 4 (opposite). This figure assumes that a child’s wellbeing is made up of nine individual interests, based on the list above. (We do not claim that this is a definitive list, but are using it as a plausible example in the paediatric healthcare context.) Each individual interest is represented by a slider on a mixer board. The key idea is that the individual interests can vary independently, and that it is the total “reading” across all of the interests that constitutes the child’s wellbeing. For simplicity, we have assumed that each interest is equally weighted (but it could be argued that some interests are more important than others, and so should be weighted more heavily in assessing the child’s wellbeing overall).

Any course of action that has an impact on a child can affect each of the individual interests differently. It is possible that one course of action can advance some of the child’s interests at the same time as it sets back some other of the child’s interests. When chemotherapy is used to treat a child with cancer, the rationale for doing this is that it promotes the child’s interests overall: that is, the setback to some interests (such as living at home, being happy, being able to play) is outweighed by the advancement of other interests (such as having the maximum possible lifespan). So the first point to make is that a setback to interests must be considered overall, as the overall impact on a child’s wellbeing. Just because there is a big setback to one of a child’s interests, this is not enough on its own to say that the child is harmed. An overall account of the impact on all of the child’s interests is required.
The next very important point is that it is only meaningful to ask whether a child would be harmed by one course of action compared to another course of action. It is necessary to compare the state of the child’s interests for the different courses of action. Take the example of assessing whether a child is harmed by the parents’ treatment choice, where this choice conflicts with the doctor’s recommended treatment. First, we would need to assess the state of the child’s interests if the parents’ option was to be followed. Secondly, we would need to assess the state of the child’s interests if the doctors’ recommendation was to be followed. It is the size of the difference between the two that matters. If the first course of action (parents’ preferred option) would have an impact on the child’s interests that is much worse than the second course of action (doctors’ preferred option), then the child is harmed by following the parents’ choice. If the difference is small overall, so that the parents’ option has a negative impact on the child’s interests compared to the recommended treatment but only by a small amount, then the first option does not harm the child.
One of the essential ideas here is that there can be a small setback to interests without it counting as a harm. Or put another way, an outcome that is less-than-the-best advancement of the child's interests is not necessarily a harm to the child. It is only harm if the difference between the best possible option and the option under consideration is big enough.
Thinking about harm:
1. Recognise multiple interests
2. Add up effects on each
3. Compare between treatment options

One complicating factor in all this is risk – where a negative outcome might occur, with some associated degree of probability. This is what makes risk different from burden. A burden is an actual setback to interests (particularly a child’s interests in being free from pain and having good physiological function), where a risk is only a possible setback. In situations where the ZPD comes into play, there are often both burdens and risks to the child at stake. We suggest that risk should be seen as one type of setback to interests. Putting a child in a situation where one or more of their interests might be set back, counts as a setback to interests in itself. Obviously being at risk of a bad outcome is not as much of a setback to interests as actually experiencing that bad outcome, but it does count for something.

The degree of setback that a risk imposes depends on both the magnitude of the bad thing that might happen, and the probability that it might happen. These are represented in Figure 6 (see over). The least problematic risks to interpret are (1) high probability of a high magnitude effect on the child, which should be counted as a significant setback to interests; and (2) a low probability of a low magnitude effect, which has a negligible effect on interests, and should not be regarded as significant. That is, risks involving high probability and high magnitude are harms. Risks involving low probability and low magnitude are not harms. Risks involving high probability of a low magnitude effect are also not harms on our definition; we specified that harm involves a big setback to interests. The most difficult type to deal with is the low probability of a high magnitude effect, such as a 1 per cent risk of death or serious brain damage. Putting a child at this sort of risk does count as a setback to the child’s interests, but not as much as a high probability of this outcome. It should be taken into account amongst the other impacts on the child’s interests, and could be regarded as significant.
Using the ZPD requires an answer to the question “is the effect on the child of the parents’ decision bad enough to count as probable harm?” This is a threshold question, and it is natural to look for clear markers of what pushes a parental decision over the line into the realm of probable harm. Is it a risk of death greater than 50 per cent? Or a reduction in life expectancy of 20 per cent or more? Or loss of more than 20 IQ points? Whilst all of these effects on a child could very plausibly be part of a picture of a setback to a child’s interests overall that is large enough to count as probable harm to a child, it is not the numbers alone that make this so. The size of the setback to interests is always relative – it depends on what would happen to the child in other possible courses of action. If the parents’ preferred option has a 60 per cent risk of death, but the clinicians’ preferred option has 40 per cent, there is only a 20 per cent increased risk of death to the child on the parents’ option, and it is the amount of increase that matters. The same sort of consideration applies to any measures or cut-off points. None of these in themselves can be an indicator of probable harm that would come from doing what the parents want, because this has to be compared to whatever the
outcome would be from doing what the clinicians want, and indeed the outcome from any other course of action that is available.

In the end, it will always be a matter of judgment as to whether the setback to a child's interests overall if the parents' decision was followed, is bad enough to count as a harm. It will depend on not only the outcomes of alternative courses of action, but also on subjective assessment of which of the many different interests of a child matter the most, what relative priority the different interests have, and how much impact on a particular interest any actual outcome will have. For example, if a course of action results in the loss of function of a child's arm, the impact of this loss on all of the child's interests must be assessed. Part of this assessment involves deciding how much it matters to have full use of both arms in relation to all the other interests of the child. Another part involves working out how much practical impact the loss of the functioning will cause. For instance, how much does the loss of functioning in one arm set back the child's interest in being able to play, and his future interest in being able to have a life as he plans it. Nothing is fully measurable here, and there is room for reasonable disagreement. Discussion with parents, colleagues, the multidisciplinary team and clinical ethics consultation are all important avenues for formulating a judgment about whether a particular course of action is harmful to the child.

In conclusion, we have argued that harm to a child:

- involves multiple interests that can vary independently
- refers to an overall assessment across all of the child's interests
- does not occur every time a child experiences a setback to his or her interests, only when the setback is of a certain magnitude
- could be constituted by a large setback to one interest or smaller setbacks to many interests
- is comparative, referring to a difference between how the child's interests are served by one option relative to another option.

There is no straightforward formula for assessing definitively whether a setback to interests is a harm. Therefore, in this exploration of the concept of harm, we have not articulated a clear boundary separating parental choices that are within the ZPD from parental choices that
are outside the ZPD. Rather, we have pointed to a series of important considerations in assessing harmfulness: the need to judge harm to the child in a multifaceted, overall and comparative way.

References


