



Navigating the Zone of Parental Discretion when Parents and Health Care Professionals Disagree

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The Zone of Parental Discretion

- ZPD is a tool for ethical deliberation
- ZPD puts into practice the key ideas of the Harm Principle
- ZPD seeks to balance 2 important values: Child's well-being/Parents' rights to decide
- ZPD useful not only in life-threatening situations



Gillam's criticism of best interests

1. “very difficult to identify the course of action that is in the child’s best interest” (hard to know a single action that maximizes the child’s well-being)
2. “best interest standard may not adequately acknowledge parental autonomy”



The Zone of Parental Discretion

"The Harm Principle recognizes that there is a morally significant gap between what is in the best interests of the child (i.e., optimal for the child) and what will cause harm to the child...The ZPD draws attention to this difference and provides a systematic way to think through these situations...(it) also accords weight to parents as decision makers for their child, weight which is often not properly taken into account when using the best interests test. The ZPD provides an ethically protected space where parents make decisions for their children even if the decisions are sub-optimal."

(McDougall et. al., 2016)



Theoretical basis for the ZPD

Zone of parental discretion is based on the following ethical claims:

1. Parents have an ethical right to make medical decisions for their children, based on their own conceptions of the good life.
2. Parents are not morally obliged to maximize the well being of their child.
3. The limit to parental authority lies at the point where significant harm is likely to be caused to the child. Parents' decisions should only be overridden if the child is likely to suffer significant harm from the decision.



The Harm Principle (Feinberg)

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)



ZPD considers:

Harm –a significant setback to interests

Interests –components of well-being

Significant setback –big difference between a child's well-being with Option A v. Option B



Substantive goods of childhood

- A child must be in reasonably good *health*
- A child's *biological needs* must be met
- A child must be provided with *intellectually engaging activities*
- A child must be involved in *meaningful relationships*
- A child must be able to enjoy *unstructured, imaginative play*
- A child must have *bodily integrity*
- A child must be *happy* (Binik,2014)

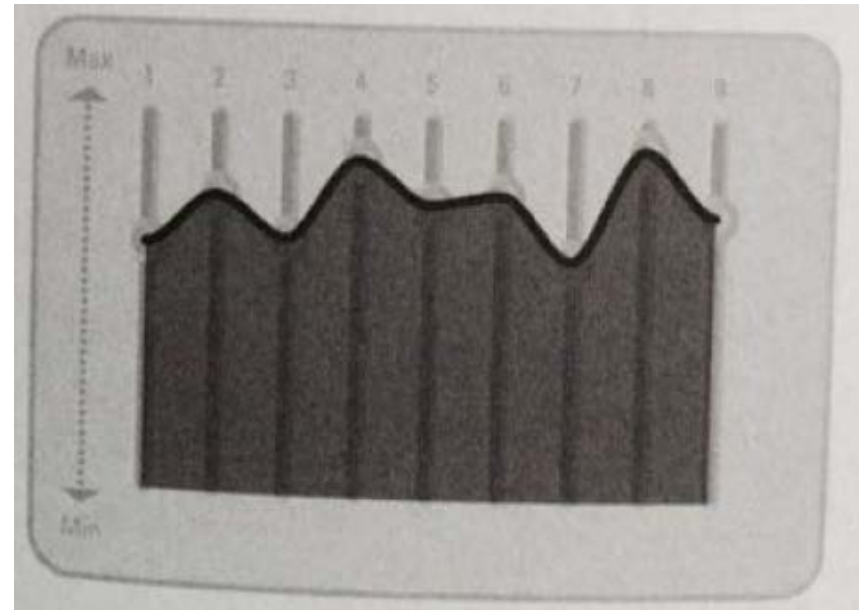
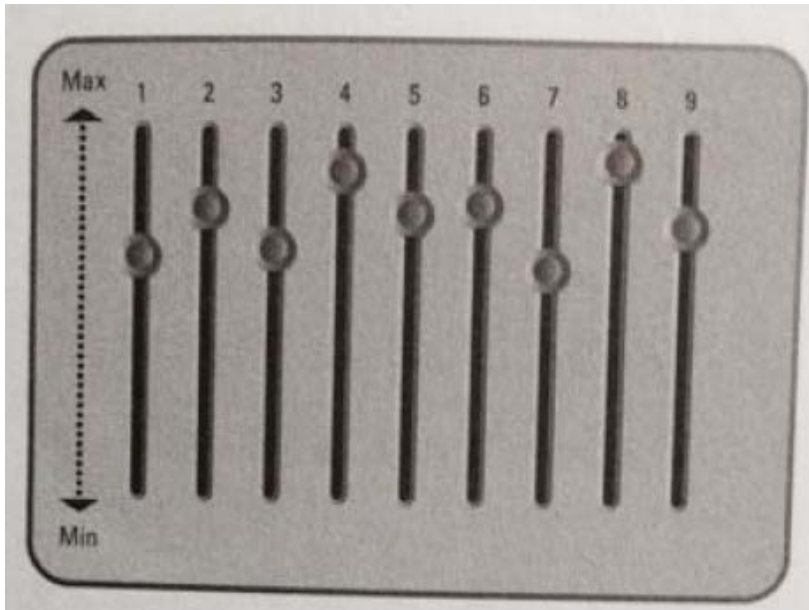


Children's interests in healthcare settings

- Being free from pain
- Having good psychological function
- Having the maximum possible lifespan
- Being happy
- Having bodily integrity
- Being able to play
- Living at home
- Attending school
- Having meaningful relationships

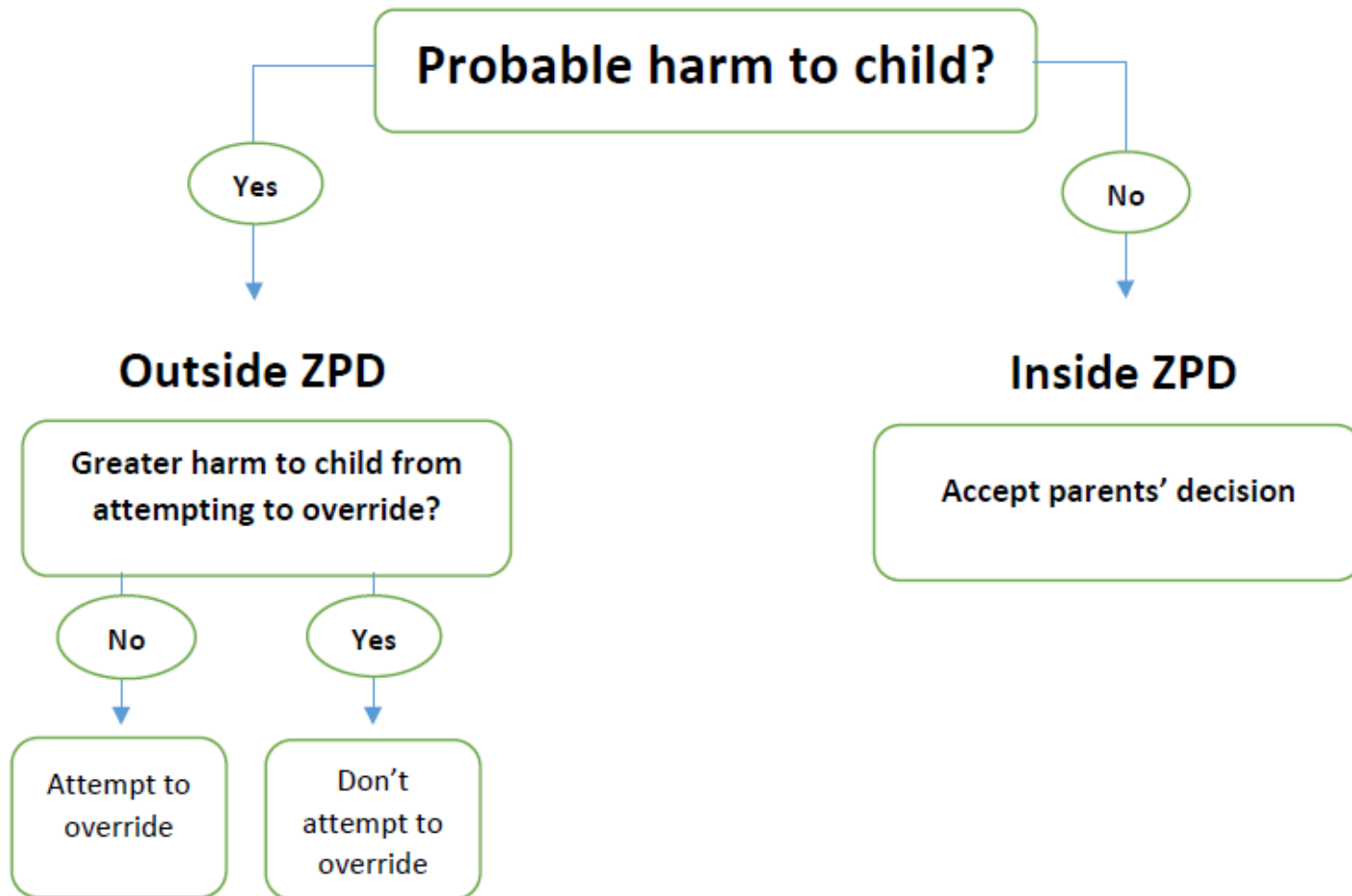
(McDougall et. al., 2016)

A child's wellbeing





Flowchart of the ZPD Process





Stage 1: Harm from parents' decisions

1. What are the parents' wishes or decision? (This is not always clear, but must be clarified.)
2. What would be the effects on the child of carrying out the decision? (This needs to be thoroughly explored, considering the full range of possible benefits and burdens to the child, and may not be clear cut.)
3. Are these effects so bad as to constitute probable significant harm to the child? (This may also not be clear cut and can be contentious.)



Stage 2: Overriding parents' decisions

1. What would be the effects on the child of attempting to or succeeding in resisting or overriding the parents' decision?
2. If there are likely to be negative effects on the child, would this constitute greater harm to the child than the harm expected from the parents' original decision?



Why should we accept sub-optimal outcomes for the child?

1. Interests are multidimensional, covering different domains of life
2. There will be different evaluations of the probability of outcomes
3. Parents are deciding on the view of their family unit-all members not just the child who is the patient.



Parents' reasons

- Gillam argues that parents' reasons are irrelevant to ZPD discussion ZPD focuses only on harm to the child.
- Reasons may be religious, cultural, alternative, and/or based on fear or misunderstanding
- If there is no harm to the child, i.e., decision is within the ZPD, then parents' reasons unlikely to impact in a negative way. Exception: Stage 2 questions focus on overriding the parents



A case to consider: Holly

Eleven year old Holly had spastic cerebral palsy and severe developmental delays. She is severely undernourished. As is common in cerebral palsy, Holly has pseudo-bulbar palsy, where the swallowing mechanism is impaired, making oral feeding very slow and difficult, resulting in coughing, choking, and regurgitation. Her parents have rejected the recommendation for a gastrostomy for fear that she will become too heavy for them to handle as she grows older. They also do not want to deprive her of the pleasure of oral feeding. Currently, Holly is on the 10th percentile for length, but far below the 3rd percentile for weight. She has severe spasticity, poor muscle bulk, and little or no subcutaneous fat. Her therapists note that Holly has extreme feeding difficulties even with thickened food. Is Holly suffering as a result of her parents' choice?

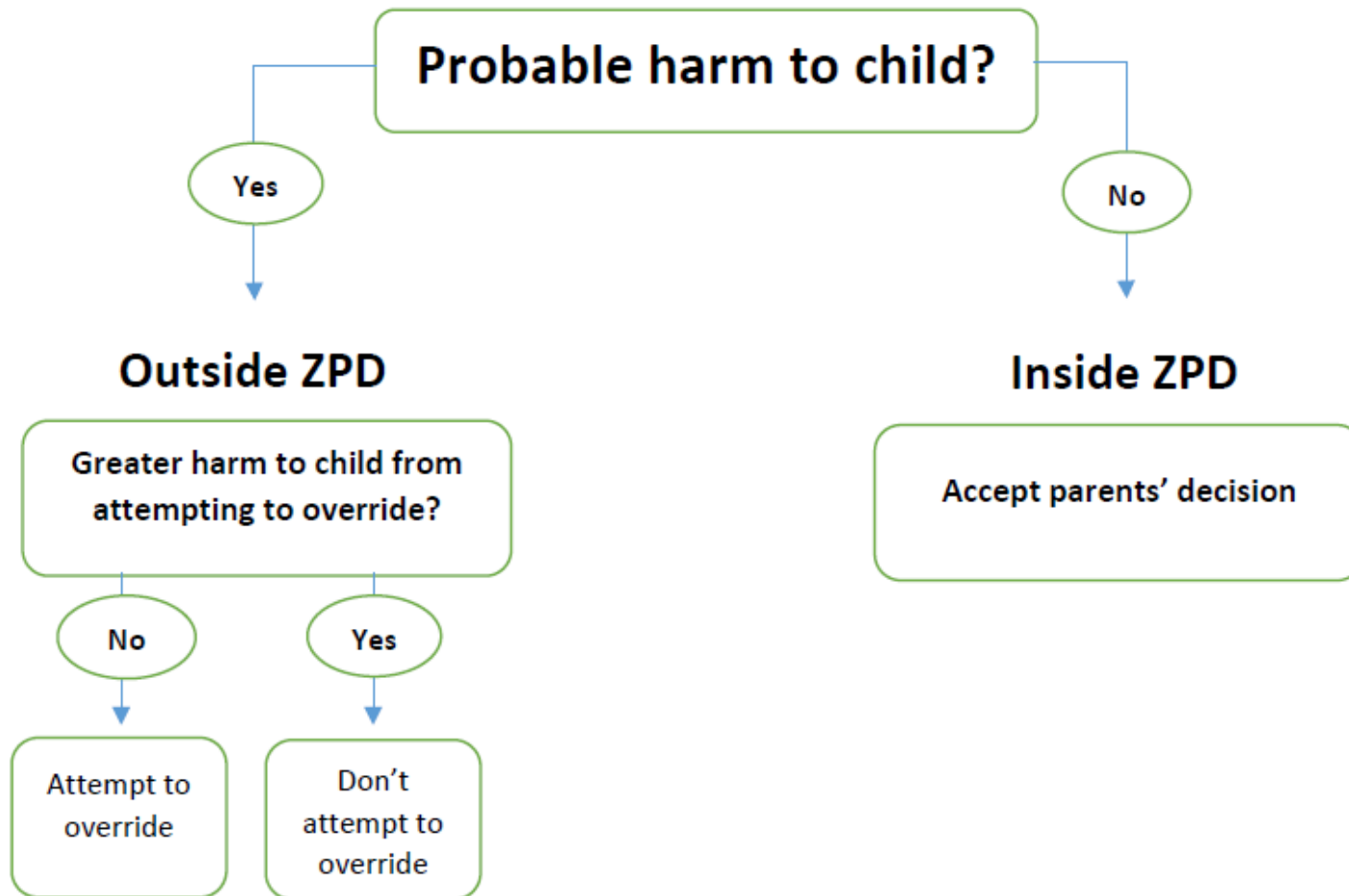


ZPD guiding questions

1. What are the parents' wishes or decision?
2. What would be the effects on the child of carrying out the decision?
3. Are these effects so bad as to constitute probable significant harm to the child?
4. What would be the effects on the child of attempting to or succeeding in resisting or overriding the parents' decision?
5. If there are likely to be negative effects on the child, would this constitute greater harm to the child than the harm expected from the parents' original decision?



Flowchart of the ZPD Process





References

Gillam, L. (2016). The zone of parental discretion: an ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child. *Clinical Ethics*, 11(1), 1-8.

McDougall, R., Delany, C., & Gillam, L. (2016). *When doctors and parents disagree: ethics, paediatrics and the zone of parental discretion*. Sydney: The Federation Press.



Thank you!

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