The best interests test: decisions about children's care

Professional guidance and law state that decisions about children's care and treatment must be made in the child's best interests, and that parents and healthcare staff ideally should both agree to the care and treatment that is to be provided. Critically discuss whether the best interests test for the care of critically ill children is fit for purpose. In doing so you should consider whether a change in the current law is required and, if so, how the law should be changed.

> Elia Davidson Law (LLB Hons) University of Edinburgh Undergraduate Essay

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Introduction

This essay will analyse whether the best interests test used by the court on occasions where parents and healthcare staff disagree about the medical treatment for children is fit for purpose. Concern has been raised that disagreement between parents and doctors may increase because of research and crowdfunding opportunities brought by the internet, therefore this issue continues to grow in relevance.¹

A particular focus will be placed on infants or young children who are unable to express a view and are therefore not *Gillick* competent.² An examination centred on critically ill children shines light on the importance of the best interests test getting it right. Instances where other treatment options are available will be explored – an issue that has captured public attention following the high-profile cases of *Charlie Gard* and *Alfie Evans*.³

¹ Dave Archard, "My Child, My Choice': Parents, Doctors and the Ethical Standards for Resolving their Disagreement' (2019) 70(1) NILQ 93, 94.

² Gillick v West Norfolk and Wisbech Area Health Authority [1986] AC 112.

³ Great Ormond Street Hospital v Yates [2017] EWHC 1909 (Fam); Alder Hey Hospital v Evans [2018] EWHC 308 (Fam).

Central to the issue is debate around where the boundary between the state and the private family sphere should be set.⁴ Concerns have been raised that the current best interests approach may fail to put enough weight on the views of parents. The option of introducing a 'significant harm' threshold will be explored, with its proponents such as Diekema arguing that it is more representative of the level at which state intervention into private family decisions is justified.⁵

It will be argued that on balance the introduction of a harm threshold carries with it significant risk and little gain. The best interest test, although not perfect, is fit for purpose and can come to compassionate and correct decisions in a particularly challenging area. It will be put forward that much of the current conflict could instead be alleviated with more investment in mediation and shared decision making.

The Current Law

When there is unresolvable disagreement between parents and healthcare professionals over treatment options for a child, court authorisation may be sought.⁶ As confirmed in *Great Ormond Street Hospital v Gard*, courts will rely on the best interests test to decide the outcome of such cases.⁷ *Gard* confirmed this to be the case even in instances where healthcare professionals elsewhere may be willing to carry out treatment. It was held that the best interest test has a long history in case law and was the established test for disagreements concerning medical treatment.⁸

⁴ Imogen Goold, Jonathan Herring and Cressida Auckland, 'Introduction' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms: Medical decision-making on behalf of children post Great Ormond St vs Yates* (Bloomsbury Publishing 2019) 2.

⁵ Douglas Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle as Threshold For State Intervention' (2004) 25(4) Theor Med Bioeth 243, 249.

⁶ G.T Laurie, S.H.E Harmon and E.S Dove, *Mason & McCall Smith's Law & Medical Ethics* (11th edn, OUP 2019) 335.

⁷ Goold, Herring and Auckland, 'Introduction' (n 4) 1.

⁸ Cressida Auckland and Imogen Goold, 'Defining the Limits of Parental Authority: Charlie Gard, Best Interests and the Significant Risk of Harm Threshold' (2018) 134 LQR 37, 39.

Although an English case, it is relevant in Scotland as the best interests test has similar use in Scots law as shown by *Finlayson, Applicant* 1989 SCLR 601.⁹

The best interests test was put forward by Beauchamp and Childress for decisions involving children.¹⁰ The use of the best interests test is a result of an inability to establish the views of young children, as such it is impossible to rely on patient autonomy, instead the best interests of patients are looked at.¹¹ A court will establish best interests by looking at a wide range of factors, a decision not being based on medical interests alone.¹² The criteria have not been pinpointed and judgements will be based on the individual facts of a case.¹³ It has been defended by the Nuffield Council on Bioethics for being 'appropriate and sufficient.'¹⁴

The best interests approach is consistent with international law.¹⁵ Article 3(1) of the UNCRC establishes that best interests should be the primary consideration in all actions considering children.¹⁶ Furthermore, under the ECHR when there is a conflict between parents' and children's article 8 rights, it is the children's rights that must be prioritised.¹⁷

Calls for A Significant Harm Threshold

In *Gard*, it was argued that there should be a 'significant harm' threshold required to be met before courts can intervene in the medical decisions of parents for their

⁹ Jonathan Brown and Sarah Christie, 'Pater Knows Best: Withdrawal of Medical Treatment from Infants in Scotland' (2020) 40(4) OJLS 682, 690.

¹⁰ Erica Salter, 'Deciding for a Child: a Comprehensive Analysis of the Best Interest Standard' (2012)33(3) Theor Med Bioeth 179, 183.

¹¹ Diekema (n 5) 245.

¹² Laurie, Harmon and Dove (n 6) 343.

¹³ Brown and Christie (n 9) 694-5.

¹⁴ David Benbow, 'An Analysis of Charlie's Law and Alfie's Law' (2020) 28(2) Med L Rev 223, 234.

¹⁵ *Ibid* 230.

¹⁶ United Nations Convention on the Rights of the Child Article 3(1).

¹⁷ Benbow (n 14) 230; Auckland and Goold, 'Defining the Limits of Parental Authority' (n 8) 41.

children.¹⁸ Although the argument was rejected, public momentum did build behind the idea of a harm threshold.¹⁹ A significant harm threshold has been campaigned for under the name 'Charlie's Law' gaining the support of some in the political sphere such as Lord MacKay.²⁰

Support for a harm threshold also exists amongst the legal and ethicist community. Commentators, such as Auckland, Goold, Nair and Wilkinson, are also of the view that reform is needed in the form of a significant harm threshold.²¹ However, others such as Birchley, Benbow and Cave remain of the view that the best interests approach is appropriate arguing against a significant harms test.²²

Parental Authority Under Best Interests

Central to the debate around the introduction of a significant harm threshold is the contention that the current best interests approach fails to afford sufficient weight to parental views. It has been argued that *Gard* demonstrated that the threshold for state intervention in parental medical decisions is 'very low'.²³ State intervention in this way arguably should require more justification than necessary at present.²⁴

¹⁸ Imogen Goold, 'Evaluating 'Best Interests' as a Threshold for Judicial Intervention in Medical Decision-Making on Behalf of Children' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms: Medical decision-making on behalf of children post Great Ormond St vs Yates* (Bloomsbury Publishing 2019) 29-30.

¹⁹ Goold, 'Evaluating 'Best Interests'' (n 18) 29-30.

²⁰ Giles Birchley, 'The Harm Threshold: A View from the Clinic' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms: Medical decisionmaking on behalf of children post Great Ormond St vs Yates* (Bloomsbury Publishing 2019) 111.

²¹ Cressida Auckland and Imogen Goold, 'Re-Evaluating 'Best Interests' in the Wake of Raqeeb v Barts NHS Foundation Trust & Anors' (2020) 83(6) Mod L Rev 1328, 1329; Dominic Wilkinson and Tara Nair, 'Harm Isn't All You Need: Parental Discretion and Medical Decisions for a Child' (2016) 42(2) J Med Ethics 116.

²² Benbow (n 14): Giles Birchley, 'Harm is all you need? Best interests and Disputes About Parental Decision-Making' (2016) 42(2) J Med Ethics 111; Emma Cave and Emma Nottingham, 'Who Knows Best (Interests)? The Case of Charlie Gard' (2018) 26(3) Med L Rev 500.

²³ Goold, 'Evaluating 'Best Interests'' (n 18) 38.

²⁴ Ibid 39.

Public backlash to the decision in *Gard* also suggests that many feel that the power of the state to intervene should be limited.²⁵

Proponents of a significant harm threshold argue that the best interests test should remain as the tool for deciding what should happen once intervention has been justified on the basis that there exists a risk of significant harm if the decisions of parents were to be followed.²⁶

Those who support the introduction of a significant harm threshold present several arguments in an attempt to establish why parents should be given such power over the medical decisions of their children.

Parents are naturally presumed to be the decision-makers for children who do not have the competence to make their own decisions.²⁷ As parents have a duty to safeguard their children, this also comes with the duty to make medical decisions for them.²⁸ McDougall argues that parents have a right to make non-damaging decisions for their children.²⁹ It is argued that this parental right to decision-making requires sufficient justification to be intervened with.³⁰

Diekema argues that it is harm that provides the ethical justification for state intervention in medical decisions.³¹ He points to JS Mill's view that the only justification for power being exercised over a member of the civil community is for the prevention of harm to others.³² He contends that it follows from this that it is at the point of harm that parental decisions can be overruled, and not when decisions

²⁵ Auckland and Goold, 'Defining the Limits of Parental Authority' (n 8) 41.

²⁶ Birchley, 'Harm is all you need?' (n 22) 111.

²⁷ Salter (n 10) 181.

²⁸ Ibid 181.

²⁹ McDougall as reflected in Giles Birchley, 'The Harm threshold and Parents' Obligation to Benefit Their Children' (2016) 42(2) J Med Ethics 123, 124.

³⁰ Birchley, 'The Harm Threshold' (n 20) 108.

³¹ Diekema (n 5) 250.

³² Ibid 250.

are simply not in a child's best interests.³³ However, Birchley has accurately criticised this argument for its failure to acknowledge that in Mill's view parental decision-making is an exercise of power, and as such a risk of harm is not required to justify state interference with it.³⁴

Furthermore, it has been suggested that a parent's right to make decisions on behalf of their children requires such decisions to benefit their children.³⁵ If parental rights require parents to nurture their children with goods, then it may be the best interests test that is a more appropriate basis for intervention than a significant harm threshold.³⁶

Parental authority being framed as a right directly clashes with the idea of children as autonomous right holders.³⁷ A focus on parental rights, therefore, carries with it the risk of undermining progress towards the recognition of children's rights.³⁸ The current best interests approach is therefore appropriate as it acknowledges the role that parents play in decision making, while also ensuring that children are recognised as rights holders.³⁹ The best interests of children should be prioritised over any right to parental authority, a significant harm threshold would risk elevating parental rights to such a level that they become nearly impossible to combat.⁴⁰

The concept of parental rights does not provide an appropriate basis for a move to a significant harm threshold. However, there may be other reasons why parental views should be given more weight.

³³ Ibid 250.

³⁴ Birchley, 'The Harm Threshold' (n 20) 112.

³⁵ Birchley, 'The Harm threshold and parents' obligation' (n 29) 124.

³⁶ Ibid 125.

³⁷ Birchley, 'Harm is all you need?' (n 22) 112.

³⁸ Jo Bridgeman, 'A Threshold of Significant Harm (f)or a Viable Alternative Therapeutic Option?

^{(2018) 44(7)} J Med Ethics 466, 468; Benbow (n 13) 236.

³⁹ Birchley, 'The Harm Threshold' (n 20) 108.

⁴⁰ Goold, 'Evaluating 'Best Interests'' (n 18) 43.

One justification for affording greater weight to parental decisions is the argument that they have a greater knowledge of their child, resulting in them being in a prime position to make decisions on their needs.⁴¹ Parents are uniquely placed as a result of the care they have for their children.⁴² Parents may also be more likely to know what decision a child would make in the future, although this may be limited as a result of the age of children.⁴³ Parents are also best placed to understand the wider familial interests at play in decisions over medical treatment and will carry the burden of the outcome of any treatment option.⁴⁴ As a result, the law must afford weight to the views of parents in decisions about the medical treatment of their child.

However, it must be ensured that not too much weight is awarded to parental views. Archard argues that it is not clear why in disagreements over medical care between parents and doctors that we should lean in favour of the parents.⁴⁵ It has been argued that in a medical context, parental claims about what is best for their child are often able to be validated or disproven with evidence.⁴⁶ Furthermore, parental decisions on the care of critically ill children are understandably likely to be emotionally charged and as a result, may be built on false hope as opposed to facts or their intimate knowledge of their child.⁴⁷

The best interests test allows for parental views to be a relevant factor in the decision-making process while ensuring that they do not become the central factor, it is this child-centric approach that should be favoured.⁴⁸

It could be argued that in instances where what is 'best' is unclear, it is unfair in a liberal democracy to impose the courts' value judgement on parents.⁴⁹ Under the

47 Ibid 237.

⁴¹ Goold, 'Evaluating 'Best Interests'' (n 18) 44.

⁴² Diekema (n 5) 244.

⁴³ Salter (n 10) 181.

⁴⁴ Diekema (n 5) 244; Salter (n 10) 182.

⁴⁵ Archard (n 1) 107.

⁴⁶ Benbow (n 14) 236.

⁴⁸ Brown and Christie (n 9) 690.

⁴⁹ Nair and Wilkinson (n 21) 117.

best interests approach it is the court's value judgement that is ultimately adhered to, this carries with it a risk of failing to respect the views of parents whose beliefs do not match up with western standards.⁵⁰ A significant harm threshold is more reflective of the existence of a diversity of outlooks in a liberal society by allowing parents to make decisions according to their value judgments at first instance, with the court only stepping in when there is a risk of harm.⁵¹ However, not all disagreements between healthcare staff and parents will be a result of value judgements. Often treatment options can be objectively assessed, and, in those instances, there is no reason why the flawed views of parents should be given precedence over the medical expertise of health staff.⁵² This is not an argument for medical paternalism, but rather points to the best interests test which allows for the views of both parents and doctors to be taken into consideration and objectively assessed.

The best interests test does afford sufficient weight to parental views. In practice, there is evidence that the court shows respect for the value of parental decisions.⁵³ Evidence also shows that doctors pay respect to the views of parents.⁵⁴ Even in those high profile cases that brought public scrutiny to the area, there were no signs of a failure to consider parental views - in the case of *Charlie Gard* considerable time was spent consulting ethics committees and gathering opinions before it was ultimately decided to seek court intervention.⁵⁵ Cases such as *Tafida Raqeeb v Barts NHS Foundation Trust and Others* also highlight that under the best interests approach the court will in some instances align with the views of parents rather than healthcare professionals, further emphasising that parental views are given weight under the current approach.⁵⁶

⁵⁴ Birchley, 'The Harm Threshold' (n 20) 108.

⁵⁰ Auckland and Goold, 'Re-Evaluating 'Best Interests'' (n 21) 1338.

⁵¹ Goold, 'Evaluating 'Best Interests'' (n 18) 47.

⁵² Archard (n 1) 107.

⁵³ Goold, 'Evaluating 'Best Interests'' (n 18) 39.

⁵⁵ *Ibid* 124.

⁵⁶ *Tafida Raqeeb v. Barts NHS Foundation Trust and Others* [2019] EWHC 2531 (Admin); Giles Birchley, 'Expert Reaction to Tafida Raqeeb Ruling From High Court' (*Science Media Centre*, 3 October 2019) <<u>https://www.sciencemediacentre.org/expert-reaction-to-tafida-raqeeb-ruling-from-high-court/</u>> accessed 11 December 2021.

Brown argues that in Scotland due to procedural differences with English law, the courts may be even more reluctant to override the views of parents in the context of the withdrawal of medical treatment from children.⁵⁷ As a result, there is even less of a need to impose a significant harm threshold into Scots law.

Furthermore, several other factors lessen the likelihood of intervention into parental medical decisions. Before doctors even consider bringing actions to the court they have to weigh up the cost of proceedings and risks of intense public scrutiny as seen in the cases of *Gard* and *Evans*.⁵⁸ Public scrutiny and resource limitations act as a barrier for intervention, ensuring that actions to interfere with parental decisions will not be taken lightly. Furthermore, the court will reject frivolous actions serving as a further threshold to applications that lack merit.⁵⁹

The threshold for intervention in the medical decisions of parents is not as low as it may first appear. Sufficient weight is given to parental views under the current best interests standard and the threshold for intervention is appropriate.

Need for Consistency

It has been argued that the best interests test holds parents to an unfair standard and that the introduction of a harm threshold would be more reflective of the autonomy they are awarded in other areas.

Diekema argues that best interests constitutes an ideal unreachable by the majority of parents.⁶⁰ He gives examples of situations where as a parent he can freely make decisions that could not be held to be in his child's best interests, such as taking his children on a drive for his morning coffee despite the associated risks of driving.⁶¹

⁵⁷ Brown and Christie (n 9) 682.

⁵⁸ Cave and Nottingham (n 22) 510.

⁵⁹ Goold, 'Evaluating 'Best Interests'' (n 18) 40.

⁶⁰ Diekema (n 5) 248.

⁶¹ Ibid 247.

Gillam argues for the introduction of a zone of parental discretion where decisions that are 'sub-optimal but not harmful' should be allowed unchallenged.⁶² It is claimed that a significant harm threshold would reflect that there are parental decisions that are not necessarily the best but should be permitted.

In England, a move to a significant harm threshold would bring the law on medical care in line with the standard for intervention in social welfare decisions. The Children Act 1989 imposes that a risk of 'significant harm' must be apparent before there can be an intervention into family life.⁶³ Sub-optimal decisions are to be tolerated in this area before the court can justifiably intervene, the lack of a similar threshold in the medical context requires justification.

On the other hand, Birchley asserts that there is a reason for this divergence between social welfare and medical care decisions.⁶⁴ He argues that there is more certainty in the outcomes of decisions in the medical care context, whereas, as the outcome of the removal of children from the family home is less certain state interference in this way requires more justification.⁶⁵ Furthermore, the reason for the threshold in the social welfare context was to avoid social engineering, a risk that does not exist in the medical care context.⁶⁶

A move to be more consistent with the approach taken in the social welfare context is not a justifiable reason for introducing a significant harm threshold for intervention into medical decisions. This is especially the case in Scotland, where there is no such significant harm threshold for intervention in social welfare decisions.

Indeterminacy of Best Interests

 ⁶² Lynn Gillam, 'The Zone of Parental Discretion: An Ethical Tool for Dealing with Disagreement
Between Parents and Doctors About Medical Treatment for a Child' (2016) 11(1) Clinical Ethics 1, 2.
⁶³ Children Act 1989 s 31(2).

⁶⁴ Birchley, 'The Harm Threshold' (n 20) 127.

⁶⁵ Ibid 127-8.

⁶⁶ Benbow (n 14) 233; Bridgeman (n 38) 469.

Aside from issues regarding consistency, other arguments have been put forward for the need to introduce a harm threshold.

Diekema argues that the best interests test is not sufficiently clear.⁶⁷ He contends that the court is not given the necessary direction it requires to make decisions.⁶⁸ Any lack of clarity may confuse healthcare professionals.⁶⁹ And it has been suggested that it may leave parents unclear about what is expected of them.⁷⁰ Arguably, children may be more vulnerable if people are left to guess what is the appropriate course of action.⁷¹ Proponents argue that a harm threshold would be a more comprehensible standard, clearing any such confusion.⁷² A clearer standard may also help to quash growing public discontent by helping the public understand why courts decide as they do.⁷³ However, due to its long history in case law, the best interests approach in the UK context does provide a clear and 'well-established analytical framework'.⁷⁴ Furthermore, the lack of rigid criteria for the test is deliberate to ensure the flexibility to judge each case on its facts and from the point of view of each child.⁷⁵

Moreover, a harm threshold may not be any clearer. Difficult value judgements would still require to be made to establish the boundary of what constitutes harm.⁷⁶ Such a threshold is still open to being shaped by the beliefs of the person utilising it.⁷⁷ Even Gillam, in their arguments for a zone of parental discretion, accepts that as interpretation will always be necessary, some lack of clarity will inevitably persist.⁷⁸

⁷⁸ Gillam (n 62) 4.

⁶⁷ Birchley, 'The Harm Threshold' (n 20) 113.

⁶⁸ Diekema (n 5) 243.

⁶⁹ Gillam (n 62) 2.

⁷⁰ Birchley, 'Harm is all you need?' (n 22) 111.

⁷¹ Salter (n 10) 194.

⁷² Birchley, 'The Harm Threshold' (n 20) 113.

⁷³ Auckland and Goold, 'Re-Evaluating 'Best Interests'' (n 21) 1339.

⁷⁴ Auckland and Goold, 'Defining the Limits of Parental Authority' (n 8) 41.

⁷⁵ Brown and Christie (n 9) 694-5.

⁷⁶ Birchley, 'The Harm Threshold' (n 20) 127.

⁷⁷ Auckland and Goold, 'Defining the Limits of Parental Authority' (n 8) 41.

Any lack of certainty in the best interest approach does not justify the introduction of a significant harm threshold. The flexibility allows for the judiciary to make a fair assessment of the individual facts of a case and it is uncertain that a harm threshold would be any clearer.

Reflective of Practice

It is argued that healthcare professionals often adapt the best interests standard and that the law should be altered to resolve any resulting inconsistencies between the law and practice.⁷⁹ A significant harm threshold may bring the law more in line with what happens in practice and as such should be introduced to ensure there is no confusion.⁸⁰ However, Birchley argues that there may be valid reasons for a difference in the approach to decisions undertaken by doctors and the approach undertaken by the court.⁸¹ If a harm threshold was introduced solely to bring the law more in line with practice it may have little impact on how decisions are made on the ground - but may still carry harmful effects in other areas such as being more evaluative in the courts and leading to issues with resource allocation.

Potential for Increased Conflict

If a significant harm threshold was introduced it would shift the focus of the court from the welfare of the child to evaluating whether parental decisions will result in harm.⁸² A harm threshold could be seen as a more head-on confrontation with parental authority.⁸³ It runs the risk of disparaging parents.⁸⁴ Furthermore, the labelling of decisions made by parents as harmful is particularly problematic in the

⁷⁹ Diekema (n 5) 248.

⁸⁰ Birchley, 'The Harm Threshold' (n 20) 125.

⁸¹ Ibid 129.

⁸² Goold, 'Evaluating 'Best Interests'' (n 18) 40.

⁸³ Auckland and Goold, 'Defining the Limits of Parental Authority' (n 8) 42.

⁸⁴ Katie Gollop and Sarah Pope, 'Charlie Gard, Alfie Evans and R (A Child): Why A Medical Treatment Significant Harm Test Would Hinder Not Help' (*Transparency Project,* 22 May 2018) <<u>https://www.transparencyproject.org.uk/charlie-gard-alfie-evans-and-r-a-child-why-a-medical-treatment-significant-harm-test-would-hinder-not-help/</u>> accessed 11 December 2021.

case of medical decisions concerning the care of critically ill children as it is in these instances where parents require compassion the most.⁸⁵ It has been argued that any decision by the court to depart from the views of the parents will be hurtful no matter how it is framed.⁸⁶ However, this underestimates the power that the use of pejorative language could have in the process of medical decision making. The use of evaluative language could cause increased conflict between doctors and parents, the mention of 'harm' may serve to poison any discussions, making a mediation process increasingly challenging if parents see this as an attack.⁸⁷

If a harm threshold were to have the effect of allowing more treatments to take place this would result in further issues. It is impossible for healthcare workers to be forced to treat patients as shown in *Re J (A Minor)*.⁸⁸ Parents may be able to fund treatment abroad, such as in the case of *Gard*, but this would not be available to all bringing in issues with distributive justice.⁸⁹ If more 'futile' treatments are allowed to take place as a result of the implementation of a harm threshold it may lead to increased conflict surrounding resource allocation.⁹⁰ It may impact the ability of healthcare professionals to treat other patients.⁹¹ While it has been argued issues with resource allocation could be tackled by giving such considerations a part in the process of carrying out a harm threshold, Birchley argues that emphasising resource limits in the decision making process on the care of critically ill children would be significantly unpopular with the public.⁹²

As a result, a significant harm threshold carries a considerable risk of increasing conflict rather than easing it, both as a result of the use of more evaluative language as well as shining light on the limited resources available in the NHS.

⁸⁵ Birchley, 'The Harm threshold and parents' obligation' (n 29) 123.

⁸⁶ Nair and Wilkinson (n 21) 118.

⁸⁷ Birchley, 'Harm is all you need?' (n 22) 124.

⁸⁸ Re J (A Minor) (Wardship: Medical Treatment) [1991] 1 Fam. 33; Benbow (n 14) 239.

⁸⁹ Benbow (n 14) 239.

⁹⁰ Birchley, 'The Harm Threshold' (n 20) 130.

⁹¹ Benbow (n 14) 238.

⁹² Birchley, 'The Harm Threshold' (n 20) 130.

Mediation

Arguments for a significant harm threshold focus on elevating parental views above that of healthcare staff, rather focus should be on processes that could help enable parties to work together.⁹³

Instead of looking to solve the conflict in the area through reform of the best interests approach, the best interests test should be kept intact but with more funding made available for the mediation process. The Nuffield Council on Bioethics has highlighted the success of mediation used in the USA as means to resolving conflict.⁹⁴ Independent mediation has the benefit of a neutral third party who may be able to facilitate communication between parents and doctors, something which is key to continuing the trust between parents and healthcare staff.⁹⁵

Benefits of mediation may not be being felt within the NHS, with Benbow highlighting its underuse as a result of a lack of financial support and knowledge of its availability.⁹⁶ Any issues with the underuse of mediation in the NHS must be resolved as this could help ensure that the relationship between doctors and parents does not break down to the point that court intervention is necessary.

There will be instances, such as in *Gard*, where conflicts can't be resolved through mediation.⁹⁷ It is in these instances that the court is best placed as an independent adjudicator to come to a final decision through the use of the best interests approach.

Conclusion

⁹³ Gollop and Pope (n 84).

⁹⁴ Benbow (n 14) 242.

⁹⁵ Dominic Wilkinson and Julian Savulescu, 'Alfie Evans and Charlie Gard - Should the Law Change?' (2018) 361 BMJ 1891, 1891; Bridgeman (n 38) 460.

⁹⁶ Benbow (n 14) 243.

⁹⁷ Cave and Nottingham (n 22) 501.

It was confirmed in *Gard* that the best interest test is the appropriate standard for the courts to use in decisions regarding the medical care of children, even when there are different treatment options available. Following this decision and public scrutiny in the area, there were increased calls for reform in the form of a significant harm threshold. However, despite concerns, the best interests approach should remain.

While some have argued that the threshold for intervention under the best interests test is too low, the impact of public scrutiny and the court's rejection of frivolous actions ensures that the threshold for intervention is not as low as it may at first appear. Additionally, arguments for increasing the status of parental rights are rejected as this may undermine progress in recognising children as autonomous rights holders.

There are important reasons for giving weight to parental views in their child's medical treatment; they are uniquely placed as a result of their motivations, intimate knowledge of their children and the burden they will take on from any treatment decisions. It may also be argued that in a liberal democracy, respect should be given to the plurality of views in society by showing greater respect to the beliefs of parents. However, not too much weight must be afforded to their views as often they may be making decisions based on emotions and hope. Weight must also be given to the views of medical professionals whose claims are often able to be validated or refuted.

Claims that the best interests test does not provide sufficient weight to the views of parents in the decision-making process are rejected. There is little evidence of doctors and the courts failing to give respect to the views of parents and examples exist of cases where the courts have accepted the views of parents as being what is in the child's best interest.

Arguments that a significant harm threshold should be introduced to ensure consistency with social welfare decisions are flawed on the basis that different risks are attached to decisions in each context, as well as no such threshold existing in Scotland. The need to introduce a harm threshold to provide clarity is also rejected. The best interests test is sufficiently flexible to deal with the individual facts of each case and a harm threshold is not necessarily any clearer.

Considerations that a harm threshold would bring the law more in line with the practice of healthcare professionals are outweighed by the potential risk of an increase in conflict through the introduction of more evaluative decision making and a spotlight being placed on limits in resources.

It is concluded that the introduction of a significant harm threshold is not the answer to the current conflict surrounding parental decisions in children's medical treatment, the best interests test is fit for purpose and should remain. Instead, much conflict could be alleviated with an increased focus on mediation and communication earlier in the decision-making process and long before instances reach the courts.

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Bibliography

Primary Sources

Alder Hey Hospital v Evans [2018] EWHC 308 (Fam)

Children Act 1989

Gillick v West Norfolk and Wisbech Area Health Authority [1986] AC 112

Great Ormond Street Hospital v Yates [2017] EWHC 1909 (Fam)

Re J (A Minor) (Wardship: Medical Treatment) [1991] 1 Fam. 33

Tafida Raqeeb v. Barts NHS Foundation Trust and Others [2019] EWHC 2531 (Admin)

United Nations Convention on the Rights of the Child Article 3(1)

Secondary Sources

Archard D, "My Child, My Choice': Parents, Doctors and the Ethical Standards for Resolving their Disagreement' (2019) 70(1) NILQ 93

Auckland C and Goold I, 'Defining the Limits of Parental Authority: Charlie Gard, Best Interests and the Significant Risk of Harm Threshold' (2018) 134 LQR 37

Auckland C and Goold I, 'Re-Evaluating 'Best Interests' in the Wake of Raqeeb v Barts NHS Foundation Trust & Anors' (2020) 83(6) Mod L Rev 1328

Benbow D, 'An Analysis of Charlie's Law and Alfie's Law' (2020) 28(2) Med L Rev 223

Birchley G, 'Harm is all you need? Best interests and Disputes About Parental Decision-Making' (2016) 42(2) J Med Ethics 111

Birchley G, 'The Harm threshold and Parents' Obligation to Benefit Their Children' (2016) 42(2) J Med Ethics 123

Birchley G, 'The Harm Threshold: A View from the Clinic' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms: Medical decision-making on behalf of children post Great Ormond St vs Yates* (Bloomsbury Publishing 2019)

Birchley G, 'Expert Reaction to Tafida Raqeeb Ruling From High Court' (Science Media Centre, 3 October 2019) https://www.sciencemediacentre.org/expert-reaction-to-tafida-raqeeb-ruling-from-high-court/> accessed 11 December 2021

Bridgeman J, 'A Threshold of Significant Harm (f)or a Viable Alternative Therapeutic Option? (2018) 44(7) J Med Ethics 466

Brown J and Christie S, 'Pater Knows Best: Withdrawal of Medical Treatment from Infants in Scotland' (2020) 40(4) OJLS 682

Cave E and Nottingham E, 'Who Knows Best (Interests)? The Case of Charlie Gard' (2018) 26(3) Med L Rev 500

Diekema D, 'Parental Refusals of Medical Treatment: The Harm Principle as Threshold For State Intervention' (2004) 25(4) Theor Med Bioeth 243

Gillam L, 'The Zone of Parental Discretion: An Ethical Tool for Dealing with Disagreement Between Parents and Doctors About Medical Treatment for a Child' (2016) 11(1) Clinical Ethics 1

Gollop K and Pope S, 'Charlie Gard, Alfie Evans and R (A Child): Why A Medical Treatment Significant Harm Test Would Hinder Not Help' (Transparency Project, 22 May 2018) https://www.transparencyproject.org.uk/charlie-gard-alfie-evans-and-r-a- child-why-a-medical-treatment-significant-harm-test-would-hinder-not-help/> accessed 11 December 2021

Goold I, Herring J and Auckland C, 'Introduction' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms: Medical decision-making on behalf of children post Great Ormond St vs Yates* (Bloomsbury Publishing 2019)

Goold I, 'Evaluating 'Best Interests' as a Threshold for Judicial Intervention in Medical Decision-Making on Behalf of Children' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms: Medical decision-making on behalf of children post Great Ormond St vs Yates* (Bloomsbury Publishing 2019)

Laurie G.T, Harmon S.H.E and Dove E.S, Mason & McCall Smith's Law & Medical Ethics (11th edn, OUP 2019) 337-341

Salter E, 'Deciding for a Child: a Comprehensive Analysis of the Best Interest Standard' (2012) 33(3) Theor Med Bioeth 179

Wilkinson D and Nair T, 'Harm Isn't All You Need: Parental Discretion and Medical Decisions for a Child' (2016) 42(2) J Med Ethics 116

Wilkinson D and Savulescu J, 'Alfie Evans and Charlie Gard - Should the Law Change?' (2018) 361 BMJ 1891