DEFENDING THE BEST INTERESTS PRINCIPLE: CARING FOR CRITICALLY ILL CHILDREN

Ambareen Huq*

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A. INTRODUCTION

The best interests (BI) principle is one of the most widely discussed principles of medical ethics and within the wider discussion on human rights. The principle is recognised as one of the core principles of the United Nations Convention on the Rights of the Child (UNCRC)[1] and is domestically entrenched within the Children Act 1989.[2] Increasingly, the BI principle has attracted widespread criticism spurred by the landmark cases of *Gard* and *Evans.*[3] Such cases have attempted without success to augment parental authority in decisions regarding the treatment of critically ill children, especially in situations where disputes arise between healthcare practitioners and parents. Considering this, I discuss the question of whether the BI principle is fit for purpose with continued reference to parental authority. In this paper, I begin by clarifying the BI principle by looking at the principle and its application at the court. By addressing the strong presumption of continued medical treatment, the point at which the court intervenes with the BI principle is addressed. The factors assessed when ascertaining the BI of the child are then clarified to understand how the diverse range of factors considered mirrors the diverse nature of cases presented. Whilst embracing critics' views, I argue that though the principle is fit for purpose, there is merit in embracing criticism to push for greater transparency of the process. The BI principle is then contrasted with the call for a significant harm threshold (SHT) as proposed in the landmark *Gard* case.[4] Whilst comparing the two approaches, the current law is defended and the wider discourse concerning parental authority is introduced. By engaging in such a discourse, the BI principle can finally be defended under a human rights framework. I argue that the BI principle is a necessary

* LLM Human Rights student at the University of Edinburgh

[1] Convention on the Rights of the Child (adopted in 1989) UNTS 1577.

[2] Children Act 1989.

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

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

safeguard for children from medical neglect. Finally, this essay justifies the court's intervention in this matter. The BI principle employed by the court effectively promotes the welfare of critically ill children as it is concerned with both private and public concerns, which is crucial for upholding values and providing binding decisions that contribute to the consistency and clarification of the law. Hence, I argue that the BI principle remains fit for purpose when it comes to the care of critically ill children. Consequently, a fundamental change in the law is not required, however, clarification over the process of ascertaining the BI of the child is advised to increase transparency and clarity between the healthcare practitioners and parents.

B. TOWARDS AN UNDERSTANDING OF THE BEST INTERESTS PRINCIPLE

Courts have understood the process of withholding or withdrawing life-sustaining treatment from critically ill children as a joint decision between doctors and those with parental responsibility.[5] Whilst individuals with parental responsibility are obligated to make decisions in accordance with the child's BI, and crucially not their own,[6] doctors, despite involving those with parental responsibility in decision-making,[7] are not legally obliged to provide treatment if the prevailing medical opinion assumes it contrary to the patient's BI or even futile.[8] It is important to note that the majority of disputes regarding life-sustaining treatment are resolved through mediation without the need for the court's intervention.[9] Consequently, in cases which do appear in front of the court, the process requires an objective exploration of a broad range of factors including medical, emotional, and all other aspects of welfare.[10] Notably, there is a strong presumption in favour of maintaining ongoing treatment.[11] The court is tasked with weighing competing factors to ascertain what is in the child's BI, which will undoubtedly vary from case to case.[12] The Children Act 1989 explicitly states that when a court determines any matter related to the upbringing of a child or the management of a child's property, the child's welfare shall be the primary consideration[13], which echoes international law standards as well.[14] Thus, it would appear as though the current legal framework, at least as a principle, is simple. It is the application of the principle that complicates the process.

Criticism of the BI principle is intriguing considering two salient opposing perspectives. Critics of the BI principle can be categorised into two main groups: those who argue that the principle is applied too objectively and those who contend that it is applied too narrowly. The first group maintains the framework concerns only the biomedical interests of the child, and consequently, children's family lives are not accounted for.[15] Indeed, Diekema criticises the

[5] *Re J (A Minor) (wardship: medical treatment)* [1990] 3 All ER 930 (CA).
[6] Children Act 1989
[7] *Glass v United Kingdom* (App No 61827/00) [2003] ECHR 719.
[8] *Re A (a child)* [2016] EWCA Civ 759.
[9] Joe Brierley, Jim Linthicum, and Andy Petros, 'Should Religious Beliefs be Allowed to Stonewall a Secular Approach to Withdrawing and Withholding Treatment in Children' (2013) 39 J Med Ethics 573.
[10] *Wyatt v Portsmouth NHS Trust* [2005] EWHC 117.
[11] *Re A (a child)* [2016] EWCA Civ 759.
[12] *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 FLR 549.
[13] Children Act 1989 s1(1).
[14] Convention on the Rights of the Child (adopted in 1989) UNTS 1577.
[15] Vic Larcher and others, 'Making decisions to limit treatment in life-limiting and life-threatening conditions in children: A framework for practice' 100 Archives of disease in childhood s3.

frequent reduction of the principle to solely objective medical interests[16], a criticism that is situated within the broader context of diminishing parental authority, a topic that will be further explored in this paper. However, this seems to be in stark contrast to the findings of Birchely who conducted interviews with clinicians to ascertain what factors contribute to the BI of the child. There was extensive reference to what is best for the child.[17] Such a conception is influenced by nuanced considerations of the wishes of the family whilst balancing any negative impact on the child.[18] Hence, when healthcare professionals evaluate the BI of the child, it is inherent to the application of the principle that they will assess the potential harms and benefits of various treatment options, including those proposed by parents. The second group argue that the principle is inherently subjective and considering differing values and how to balance competing childhood interests it is difficult to conclude the BI.[19] Such criticism alludes to the idea that there is inconsistency in the application of the principle. However, I believe that this more accurately points to the diverse nature of cases presented and the diverse factors the courts must account for when ascertaining the BI of the individual child. Such an approach seems to be embraced by the court. In *Barts Health NHS Trust v Raqeeb*, although doctors considered the continuation of Tafida's life-sustaining treatment was not in her BI, Justice McDonald undertook a careful and balanced approach to identify what was in her BI.[20] During the process, Justice McDonald asserted that to answer the objective BI test, subjective or highly valued ethical, moral and religious factors intrinsic to the child must be assessed.[21] More recently, in *Re Archie Battersbee* the court reaffirmed such a stance by drawing the parameters of the BI principle beyond the medical issues at stake, and campaigning for the child, his personality and wishes at the centre of the process and not viewing him as simply the raft of medical complexity.[22] Whilst I believe it is clear that the BI principle is broad and value-laden, and consequently fit for purpose, there is merit in acknowledging the criticisms. Such views draw attention to the lack of transparency in the process of identifying the BI of the child and indeed the factors that influence it. Thus, it would be beneficial to the treatment of critically ill children if the law better clarified the criteria which would have implications for greater transparency between healthcare professionals and parents.

C. CHARLIE'S LAW: A CALL FOR THE SIGNIFICANT HARM THRESHOLD (SHT)

As alluded to earlier in this paper, *Gard* was a significant case within the discourse concerning the treatment of critically ill children, not least because of its calling into question who has the ultimate say over a child's medical treatment. But further, it has given rise to questions regarding the relationship between the state and its citizens, and questions where the legitimate boundaries for state interference in family and private life should be set. In *Gard*, the parents of the infant, diagnosed with infantile-onset encephalomyopathic mitochondrial DNA depletion syndrome, a rare condition, contested the application of the BI principle. A

[16] Douglas S Diekma, 'Parental Refusal of Medical Treatment: The Harm Principle as Threshold for State Intervention' (2004) 25 Theoretical Medicine and Bioethics 243.
[17] Giles Birchely, 'The Harm Threshold: A View from the Clinic' in Imogen Goold, Jonathan Herring and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms* (1st edn, Hart Publishing 2019) 107.
[18] Ibid.
[19] Erica K Salter, 'Deciding for a child: a comprehensive analysis of the best interest standard' (2012) 33 Theoretical Medicine and Bioethics 179.
[20] *Barts Health NHS Trust v Raqeeb* [2019] EWHC 2530.
[21] Ibid.
[22] *Dance & Ors v Barts Health NHS Trust (Re Archie Battersbee)* [2022] EWCA Civ 1106.

disagreement between the parents and Great Ormond Street Hospital (GOSH) regarding the administration of experimental treatment. GOSH maintained that Charlie should not receive the treatment and was unwilling to administer it, despite the parents' wish. Whilst typically a refusal by a hospital to administer treatment would preclude the possibility of receiving such treatment, a hospital in the US expressed willingness to provide the experimental nucleoside therapy. The parents were seeking permission to transfer Charlie to a hospital that was willing to treat their son. With the plausibility of receiving treatment elsewhere, the case introduced a new question to the court regarding the application of the BI principle. Since the parents were not attempting to persuade GOSH to treat Charlie, the key issue became whether a specific threshold should be established before the court intervenes in parents' medical decisions regarding their children. A SHT was suggested which would declare that the court could intervene only at the point at which the parent's decision exposed the child to a risk of serious harm. The proposal was promptly rejected by the court with Lady Hale explicitly supporting the BI asserting that parents cannot demand treatment that is not in the BI of the child. Though the proposal was rejected, the public endorsement of the threshold has greatly contributed to the widespread campaign for the adoption of what is now understood as Charlie's Law.[23]

D. DISPUTING THE ASSUMPTION OF PARENTAL AUTHORITY

It is evident that the campaign for a SHT is based on the assumption that parental authority should be sovereign. However, as will now be discussed, this assumption is not, and should not be considered, absolute. The SHT relies upon the assumption that parental authority should prevail in situations of disagreement, which means it is useful to assess the concept as part of the framework governing the *zone of parental discretion*. This zone safeguards a realm where parents can rightfully make decisions for their children, even if these choices are suboptimal and not the absolute best.[24] Within this realm, parental decisions that are *good enough* suffice as long as they do not cause significant harm to the child.[25] Within the available literature, it is uncontroversial to assert that parents maintain a justified right to make decisions for their children with this being limited by the principle of significant harm. Certainly, a common suggestion is that parents maintain an ethical right to make medical decisions for their children, guided by their understanding of a good life.[26] Others justify parental authority not merely through presumption but by invoking John Stuart Mill's harm principle.[27] Within this perspective, parental autonomy can be seen as an extension of personal autonomy. However, adopting this view should be criticised for the implications it has on how we view the parent/child/doctor relationship, which is fundamentally different from the relationship between the state and the individual. Indeed, the freedom of an individual to make choices as to how they lead their life does not extend to nor encompass the freedom to make parental choices, that is choices over another human being's life.[28] As Taylor crucially reminds us, the

[23] 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* (1st edn, Hart Publishing 2019) 2.
[24] 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 Clinical Ethics 1.
[25] Ibid.
[26] Ibid.
[27] Douglas S Diekma, 'Parental Refusal of Medical Treatment: The Harm Principle as Threshold for State Intervention' (2004) 25 Theoretical Medicine and Bioethics 243.
[28] David Archard, Emma Cave, and Joe Brierley, 'How should we decide how to treat the child: harm versus best interests in cases of disagreement' (2023) 0 Medical Law Review 1.

most important component of parental responsibility is that the parental role is one of responsibility to children rather than proprietary rights over them.[29] Thus, it is my view that permitting parents to make medical decisions that are not in the BI of the child is inappropriate considering the baseline assumption of parental authority is not correct and encouraging such a shift in the law would be synonymous with viewing children as property of their parents. Indeed, the BI principle within this context remains an effective system to protect children from this form of exploitation.

E. HISTORICAL CONTEXT AND THE DEVELOPMENT OF DIMINISHING PARENTAL AUTHORITY

In high-profile cases such as *Gard and Evans*, the courts made it clear that they retained jurisdiction to intervene whenever a child's welfare is an engaged concern. However, in their judgements, it was not made clear where this jurisdiction is found. The court's *parens patriae* doctrine, the foundation of its inherent jurisdiction, has been developing since feudal times. This concept originated from the idea that the monarch, acting as the ultimate authority, had jurisdiction over justice and even had a parental role, known as *parens patriae*, to care for those who could not care for themselves in the country.[30] Feudal lords held this power until it was conveyed to the courts in the sixteenth century. Consequent case law developed in the 19th century appears to further support this role. Indeed, in *Re Flynn (1848)* the court maintained this role in order to protect children from their parents' decisions where again their safety and welfare would be significantly impacted by the decision.[31] *Re Gyngall* upheld the role of the court by asserting that the court, under the Crown's prerogative, is situated as the ultimate parent of children. The court is obligated to wield its jurisdiction in accordance with the actions of a wise, affectionate, and careful parent.[32] Until this point, it would appear that the powers of the court were limited by a *parent's know best* view which was gradually subordinated by various statutes and case law in the latter half of the 19th century. Indeed, the Guardianship of Children Act 1886 standardised parental rights and made the welfare of the child a statutory factor, whilst the Custody of Children Act 1891 gave the court power to interfere with parental rights in the interests of the child. *Re McGrath (Infants)*[33] unequivocally emphasised that the court's paramount concern is the comprehensive welfare of the child. Such a stance was repeatedly affirmed during the first half of the 20th century through statutory and case law developments.[34] Indeed, *J v C* established that parental rights had been subordinated by the paramountcy of the BI of the child.[35] The stance of the court was explicitly reaffirmed in Gillick suggesting that in common law common law parental rights have never been treated as sovereign or beyond review and control**.** Indeed, parental rights exist for the performance of their duties and responsibilities to the child, thus such rights must be exercised with regard to the BI of the child.[36] By assessing the historical intervention of

[29] Rachel Taylor, 'Parental Decisions and Court Jurisdiction: Best Interests or Significant Harm?' in Imogen Goold, Jonathan Herring, and Cressida Auckland (eds) *Parental Rights, Best Interests and Significant Harms* (1st edn, Hart Publishing 2019) 141.
[30] Graeme Laurie,'Parens Patriae Jurisdiction in the Medico-Legal Context: The Vagaries of Judicial Activism' (1999) 3 Edinburgh Law Review 95.
[31] *Re Flynn* (1848), 2 DeG. &Sm. 457, 64 E.R. 205.
[32] *R v Gynall* (1893) 2 QB 232.
[33] *Re McGrath (Infants)* [1893] 1 Ch 143.
[34] Cressida Auckland and Imogen Goold, 'Parental Rights, Best Interests and Significant Harms' (2019) 78 Cambridge Law Journal 287.
[35] *J v C* (1970) AC 668.
[36] *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] A.C. 112.

the court, the reliability of the institution as a safeguard of children's welfare can be established.

F. A HUMAN RIGHTS DEFENCE OF THE BEST INTEREST PRINCIPLE

The final argument I offer in support of the BI approach to caring for critically ill children is the human rights one. I maintain that the BI principle remains an effective way of protecting children from medical neglect, at least in a situation where the SHT is the alternative option. Indeed, within the human rights law sphere, the vulnerability of children continues to be the driving force for advancing their rights. The preamble of the UNCRC highlights the UN's acknowledgement that childhood is deserving of special care and assistance.[37] It serves as a reminder that due to the physical and mental immaturity of children, they require particular safeguards and care.[38] Accordingly, the BI of children should be the primary consideration in all actions considering children.[39] The treatment of children within the private sphere is a matter of particular concern when considering children's rights. Generally, the state upholds the family as champions of children's rights by acknowledging a zone of privacy within the household.[40] However, such a position has come under rightful scrutiny as privacy and autonomy have been positioned as a cover for child abuse and neglect.[41] As Cronin elucidates, to compensate for *natural guardians'* failure of duty, there is a shift of responsibility to state-appointed experts, including medical practitioners, to compensate for this shortcoming.[42] A crucial aspect of the discussion on the domestic abuse of children revolves around the issue of medical neglect. Whilst it can be contested what constitutes medical neglect of children, a constructive interventionist approach seems appropriate considering its capacity to illustrate the complexity of the situation.[43] Such an approach identifies what the child needs and how best this can be provided.[44] Under this framework it would appear that adopting the SHT considering its willingness to overlook the BI of the child, runs the risk of permitting medical neglect of children, thus violating their rights. Hence, the BI principle remains well-suited for protecting the rights of critically ill children. It is noteworthy that there appears to be a literary deficit in explicitly discussing the link between the pursuit of the SHT and its potential to promote medical neglect of children. Such an exploration should be encouraged to better clarify how we promote children's welfare, especially those who are critically ill and lack autonomy in making decisions about their medical care.

G. DEFENDING THE INVOLVEMENT OF THE COURT

This paper has maintained that the current law governing the care of critically ill children through the BI principle is still very much an effective means for promoting children's welfare. Within this wider discourse lies the question regarding whether the court is the best forum for dealing with disagreements regarding the treatment of critically ill children. Whilst I am of the view that a judicial process which employs the BI principle is still fit for purpose, it would be fruitful to engage with this issue further to establish why this is the case. Critics of the process

[37] Convention on the Rights of the Child (adopted in 1989) UNTS 1577.
[38] Ibid.
[39] Convention on the Rights of the Child (adopted in 1989) UNTS 1577 s3(1).
[40] Kieran Corin, 'What About Children's Rights?' (2011) 62 The Furrow 387.
[41] Ibid.
[42] Ibid.
[43] Howard Dubowitz and others, 'A conceptual definition of child neglect' (1993) 20 Criminal Justice and Behaviour 2.
[44] Ibid.

suggest that court involvement impinges on a fair and expedient process.[45] However, such requirements are often competing within this context. Indeed, principles of fairness, such as due process, potential for deeper reflection, gathering of all relevant information and potential to contest a decision, can result in decisions not being expedient.[46] Simultaneously, an expedient process, such as unilateral and final decision-making by a clinician, would not be fair. Furthermore, appeal mechanisms are pertinent to safeguard against the power of the state and help prevent subpar or arbitrary decision-making.[47] Even within the context of the *Gard* case, the applicants appealed to three tiers of the court, hence it is clear that even if individual courts have the capacity to make decisions quickly, it is not necessarily conducive to a fair process. Instead, the current involvement of the court supports the values required in such cases. It is also important to remember that the issue of treating critically ill children is a matter of both private and public concern. The private element is clear in that applicants are private individuals bringing cases forward against medical practitioners, however, the decision of the court has implications for the public too. Indeed, the court will make public statements and provide binding decisions.[48] Whilst private individuals may be faced with decisions in clear opposition to their wishes, this may be necessary in order for the courts to clarify the law and the process of decision-making. It is further worth reminding that the application of the BI principle necessitates analysis of the interests of the individuals involved. Such a trade-off further promotes long-term benefits to the consistency and clarification of the law.

Further criticism of the court's involvement in this process surrounding *Gard* includes the issue of adversarialism.[49] It may be challenging to prevent conflict and negative emotions, as either compelling healthcare practitioners to act against their conscience or discontinuing treatment against parents' views is likely to generate such tensions, even with a highly sensitive decision-making process. Consequently, the involvement of the court may be ideal in disputes considering its independent nature. Though some adversarialism is inevitable, addressing concerns regarding cost and delay related to the process may be plausible through empowering quasi-judicial multi-member tribunals which are often multidisciplinary and can assemble panels with both clinical and ethical expertise.[50] For the UK to extend its tribunal process into this area it may allow the law to operate with greater flexibility, speed, and inquisitorial capacity, which provides potential for the fair and expedient forum campaigned for by Wilkinson and Savulescu.[51] Indeed, tribunals are not rigidly bound by rules of evidence, allowing them to operate more efficiently and explore a wider range of issues beyond the constraints imposed by the involved parties. There is developing support for the use of clinical ethical committees.[52] These committees centre their concern around the provision of ethical advice regarding the BI of critically ill children. It is hoped that utilising these services as a primary forum for these kinds of disputes would reduce the consequences of the limitations of the law. That is to say, they carry the potential to mitigate costs to both

[45] Dominic Wilkinson and Julian Savulescu, 'Hard lessons: learning from the Charlie Gard case' (2018) 44 Journal of Medical Ethics 44.
[46] Eliana Close and others, 'Charlie Gard: in defence of the law' (2018) 44 Journal of Medical Ethics 476.
[47] Ibid.
[48] Ibid.
[49] Dominic Wilkinson and Julian Savulescu, 'Hard lessons: learning from the Charlie Gard case' (2018) 44 Journal of Medical Ethics 44.
[50] Terry Carney and David Tait, *The Adult Guardianship Experiment: Tribunals & Popular Justice* (7th edn, Federation Press 1997) 229.
[51] Dominic Wilkinson and Julian Savulescu, 'Hard lessons: learning from the Charlie Gard case' (2018) 44 Journal of Medical Ethics 44.
[52] Richard Huxtable, 'Clinic, courtroom or (specialist) committee' (2018) 44 Journal of Medical Ethics 471.

parties, including financial, legal and emotional costs considering the sensitive nature of such cases.[53] Certainly, it seems evident that clinicians, patients, and the court share the belief mediation should be pursued prior to resorting to legal intervention. Healthcare practitioners frequently advocate for reaching a compromise with parents before escalating the matter to court.[54] Additionally, for parents, involvement in the court process can be distressing.[55] Francis J in *Gard* further stressed that mediation should be attempted in all cases, even if all that is achieved by this is a greater understanding of each party's position.[56] There are clear similarities between the tribunal and ethical committee frameworks, however, I am of the view that the former is more appropriate within this context. Though both models allow for obtaining ethical and medical evidence, tribunals are able to represent the state and their decisions are generally legally enforceable. Whilst the tribunal will not necessarily be able to form binding precedents, it still maintains a duty to provide publicly available reasons for the decisions. Hence the model could promote transparency and contribute to greater certainty of future decision making.

H. CONCLUSION

Therefore, this essay has expressed that the BI principle remains a crucial and effective framework for the care of critically ill children. The prevailing legal framework, grounded in both domestic and international laws, emphasises collaborative decision-making amongst healthcare practitioners, parents, and the courts. Whilst critics debate the breadth and narrowness of its application, a nuanced understanding reveals that practitioners consider a diverse range of factors, including family wishes. Criticisms mirror the diversity of cases requiring the BI principle, but they overlook evolving case law acknowledging subjective and ethical factors. Cases like *Raqeeb* and *Batersbee* demonstrate the court's openness to incorporating intrinsic child factors. Whilst embracing the criticisms, I contend that concerns can be addressed within the existing legal framework. I have then assessed the suitability of the BI principle in light of the currently widely campaigned alternatives. As such, the shortcomings of the proposed SHT, as raised in *Gard,* have been used to justify the suitability of the BI principle. The rejection of Charlie's Law has been defended, emphasising the continued importance of the BI principle in protecting children from potential harm. The analysis contended that the assumption of absolute parental authority, as implied by the proposed legal reform, is flawed. Parental authority is not absolute and the BI principle serves as a necessary safeguard against potential harm caused by suboptimal parental decisions. By looking at the historical context of diminishing parental authority, the court's traditional role in intervening when a child's welfare is at stake has been used to further justify the reliability of the principle. I further presented the human rights perspective as a strong defence of the current law, emphasising the vulnerability of children and the need for their BI to be the primary consideration. Within the framework of human rights, the BI principle is posited as a robust mechanism for protecting children from medical neglect. Finally, this essay has defended court involvement in disputes, countering critics who argue for alternative forums. I have maintained that the judicial process of employing the BI principle is justified by the court's concern for fairness, due process, and the safeguarding of both private and public concerns. Thus, this paper has argued that the BI test when caring for critically ill children,

[53] Ibid.

[54] Giles Birchely and others, 'Best interests' in paediatric intensive care: an empirical ethics study' (2017) 102 Archives of Disease in Childhood 930.

[55] Richard Huxtable, 'Clinic, courtroom or (specialist) committee' (2018) 44 Journal of Medical Ethics 471.

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

as embodied in the current legal framework, is argued to be fit for purpose. Whilst acknowledging criticisms, the paper asserts that the existing system is effective, adaptable, and aligned with human rights principles. The call for greater transparency and clarification of criteria within the law can be met without necessitating a fundamental shift away from the BI principle.