

Defining the Limits of Parental Authority: Charlie Gard, Best Interests and the Risk of Significant Harm Threshold

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Legislation:

Children Act 1989

Cases:

Great Ormond Street Hospital v Yates [2017] EWCA Civ 410

Re King [2014] EWHC 2964 (Fam)

Re G [2012] EWCA Civ 123

Portsmouth Hospitals NHS Trust v Wyatt and another [2005] EWCA Civ 1181

Re T. (A Minor)(Wardship: Medical Treatment) [1997] 1 WLR 242

Barnett London Borough Council v AL [2017] EWHC 125

Re C (Children)(Child Care: Choice of Forename) [2016] EWCA Civ 374

In *Great Ormond Street Hospital v Yates* [2017] EWCA Civ 410, the Court of Appeal considered the case of Charlie Gard and his parents' fight to have him receive experimental nucleoside therapy for mitochondrial DNA depletion syndrome. This progressive and ultimately fatal condition had left Charlie unable to move his arms and legs or to breathe unaided, as well as affecting his heart, liver and kidneys. He was deaf, suffered from frequent epileptic fits and was severely brain damaged. Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) sought a declaration that artificial ventilation could be withdrawn from Charlie and palliative care provided; a view opposed by his parents. While agreeing that his current life was not worth sustaining, Charlie's parents wanted to take him to the United States to receive nucleoside therapy, believing it might improve his condition. Although GOSH had been happy to try the therapy, before it could be administered Charlie suffered a series of seizures, which GOSH believed had left him with such severe brain damage that any treatment was now effectively futile. They sought a further order that it would not be in Charlie's best interests to undergo nucleoside therapy.

Mr Justice Francis in the High Court considered the application under the well-established principle that in cases of dispute over the medical treatment of a child, the court has inherent jurisdiction to make a decision based on the child's best interests.

In setting out the law, Francis J. referred to the case of *Portsmouth Hospitals NHS Trust v Wyatt and another* [2005] EWCA Civ 1181, in which the Court of Appeal emphasised that the court's paramount concern was the welfare of the child, and though there was a strong presumption in favour of prolonging life, this was not "irrebuttable". He found for GOSH, concluding that it was almost certainly not possible to reverse Charlie's brain damage, and so the therapy would only prolong his suffering. He therefore agreed with GOSH that the treatment was effectively futile and thus not in Charlie's best interests.

On appeal, counsel for Charlie's parents contended that this was a case in which the court did not have automatic authority to decide on a child's medical care. In the Court of Appeal the judges understood the argument for this view to be that, following *Re King* [2014] EWHC 2964 (Fam), in situations where there is a viable alternative course of treatment, courts can intervene only where there is a risk that the parents' proposed course of action may cause "significant harm". Counsel dubbed these "Category 2" cases, while those where the court had inherent jurisdiction were referred to as "Category 1" cases (essentially all other related cases). However, counsel argued during the application for appeal to the Supreme Court that the Court of Appeal had misunderstood the argument put forward when it had focused on the viability issue. The Category 1 / Category 2 distinction was not a question of viability, but was about whether the Court *must* in the circumstances adjudicate on the issue, or not. Category 1 cases, it was suggested, were those where the court had no choice but to adjudicate because it was confronted with a justiciable dispute between two parties (that is, court adjudication that had been sanctioned by law or established practice) which could not otherwise be resolved. In such cases, it was simply not possible for the parent's wishes to be determinative, as there was some independent force which prevented them from making the decision (the parents could not, for example, *force* clinicians to treat their child). The only sensible basis on which to adjudicate between these parties must be on the basis of the child's best interests.

This "rock of immobility" was not, however, present in Category 2 cases such as this one. Here, there was no impasse between parties, as the parents had another doctor willing to provide the therapy to Charlie, therefore the Court's jurisdiction was not invoked. For the Court to *have* jurisdiction to involve itself in a parental decision, there would need to be some grounds for this. The Court could not, the appellants argued, simply involve themselves in any parental decision and override it at will: that would be a gross invasion of private and family life and hence in breach of constitutional protections and / or Articles 2, 3 and 8 of the European Convention on Human Rights. In Category 2 cases, therefore, there must be some threshold before the Court can override the decision of parents. This cannot be 'best interests' as this would remove any distinction between legitimate state action and parental responsibility, leaving every parental decision open to being overturned by the Court on the basis of its own alternative evaluation of 'best interests'. Instead they invoked the threshold found in section 31 of the Children Act 1989, that the parents' decision

could be interfered with only where it carried a risk of significant harm to the child. The court could not therefore interfere with the parents' decision to accept alternative treatment from another physician unless this would result in significant harm (which, they argued, it did not). The impact would be to retain parental authority, which could not be undermined without sufficient reason.

The appellants also emphasised that GOSH's application could only relate to whether it was lawful to withdraw treatment (upon which the Court could adjudicate). It did not extend to enabling the Court to make any decision about what *should* happen to Charlie, including whether he could be treated by another medical practitioner at the parents' request. In making an order that prevented Charlie from being taken to America, the Court had gone beyond its jurisdiction. No question of welfare had been raised and therefore section 1 of the Children Act was not triggered and the Court had no power to involve itself in a parental decision. Section 1 was to be read through the lens of section 3 of the Human Rights Act 1998, preventing simply any issue concerning the welfare of a child, even the most trivial, being brought to the courts.

At issue was whether the 'risk of significant harm' threshold in s 31 of the Children Act, which determines when the court may make care or supervision orders, should be applied to disputes about a child's medical care generally. Under the Children Act 1989 if a local authority wishes to intervene in the upbringing of children it normally does so through a care or supervision order. Under section 31 those orders can only be made if the "significant harm" threshold is met and it is in the best interests of the child to make the order. If the dispute is between two parents, then the court will simply make the order based on the best interests of the child. The Children Act applies to medical decisions via its general application to the upbringing of children, which includes disputes between parents and medical professionals, but s 31 does not apply to such cases and so they are decided on best interests alone. The court can also make an adjudication in disputes between medics and parents through its inherent jurisdiction which, as it operates outside the Children Act, means section 31 does not apply to it either. This jurisdiction is based on common law and orders are made based on the child's best interests.

GOSH had brought their application under both the inherent jurisdiction, and as a specific order application under section 8 of the Children Act. Under either source, Counsel argued to the Supreme Court, the case ought not to have been justiciable. The important question was therefore whether this 'risk of significant harm' test should be *imported* to Category 2 cases brought under the inherent jurisdiction (or, indeed, section 8). The broader legal question, resting on the references to Article 8 and constitutional principles, was who has the ultimate authority to make medical decisions on behalf of a child – the parents or the courts?

In support of their position, the appellants cited *Re King*, a case concerning a disagreement over the treatment of a child with a brain tumour. As a result of that dispute, the family removed the child from the hospital, and took him to Spain, where

they were subsequently arrested and brought back to England. The Court was asked to determine whether he should receive the treatment preferred by the parents or by the hospital. By the time of the hearing however, the parties had agreed a treatment plan. As the child was by that time a ward of court, Baker J. was nonetheless required to approve the plan. In his judgment he said that the State had “no business interfering with the exercise of parental responsibility unless the child is suffering or is likely to suffer significant harm as a result of the care given to the child not being what it would be reasonable to expect a parent to give” [31].

They also cited *Barnett London Borough Council v AL* [2017] EWHC 125, in which Mr Justice McDonald had said that the local authority had met the criteria for granting leave to make an application under the inherent jurisdiction set out in section 100(4) of the Children Act, which includes a requirement that “there is reasonable cause to believe that if the court’s inherent jurisdiction is not exercised with respect to the child he is likely to suffer significant harm”.

However, McFarlane L.J. held that based on a long line of cases, it was clear that the best interests test was the established approach to cases where medical care decisions are disputed. Dealing with the argument in relation to *Re King*, McFarlane L.J. emphasised that the decision fell under section 31 because it related to the removal of Aysha from the hospital and the local authority’s wish to track down the parents and take him into care for his own safety, and hence pertained to the legitimacy of action by the local authority. It did not relate to a dispute over his medical care.

Similarly, *Re C (Children)(Child Care: Choice of Forename)* [2016] EWCA Civ 374 and *Barnett*, he stated, were cases in which the significant harm threshold was rightly invoked because both were decisions about whether the local authority could make an application under the inherent jurisdiction. The purpose of the Children Act generally, and section 100 specifically, was to narrow the use of inherent jurisdiction applications by local authorities, which had up until the Act been used as a mechanism for achieving control over the lives of children and their families [107]. Section 100 applied to restrict local authorities’ access to the inherent jurisdiction, and should not be read more widely. By contrast, hospitals were not required to access the inherent jurisdiction via the section 100 pathway. They could, as GOSH had done, apply directly under that jurisdiction for a best interests decision to be made.

On these grounds, Mr Justice McFarlane rejected the attempt to import any test or new category of case that allowed for court involvement in a choice between viable treatments only where the significant harm threshold was breached. He also cited with approval the implicit refutation of a threshold made by Lady Justice Butler-Sloss in *Re T. (A Minor)(Wardship: Medical Treatment)* [1997] 1 WLR 242, who stated:

“it is clear that when an application under the inherent jurisdiction is made to the court, the welfare of the child is the paramount consideration. ... as Sir Thomas Bingham MR said in *Re Z*, the court decides and in so doing may overrule the decision of a reasonable parent.”

In the view of McFarlane L.J., the Court should not engage in any evaluation of the reasonableness of the parents' case nor 'any other factor or filter before it embarks upon deciding what is in the best interests of the child' (at [94]). Risk of significant harm played no part in the best interests test as a separate filter before the court could become involved. Thus, the Court of Appeal affirmed the long-established position that while parents have power to make many decisions on behalf of their children, where there is debate between medical professionals and parents, it is the court that decides, and that it does so on the basis of what is in the child's best interests. He further stated that there was not, on the facts, actually an alternative course of action open to Charlie and hence the question of a Category 2 case did not actually arise.

The Supreme Court, in rejecting permission to appeal, did not engage with the Category 1 and 2 distinction directly. Rather, it emphasised that whether an application is made for a specific issue order under the Children Act or under the Court's inherent jurisdiction, the principle remains the same that where there is a dispute about a child's welfare, it must be resolved by reference to the child's best interests. It effectively stated that the Court *did* have authority to intervene in a parental decision about choice of treatment (Category 2) when Lady Hale stated "parents are not entitled to insist upon treatment by anyone which is not in their child's best interests". Further, it framed GOSH's application as a request for "guidance as to what treatment is and is not in the best interests of their patients", and stated that the significant harm test did not apply to such cases. The point was clearly made then, that whenever a medical decision about a child resulted in concern being raised to the Court, the Court could legitimately rule upon it by application of a best interests analysis. It was also made clear that a hospital in GOSH's position was entitled to bring proceedings of this kind.

Additionally, the Supreme Court stated that in any decision where both the parents' and the child's rights under Article 8 of the European Convention on Human rights were at stake, the child's rights were of paramount consideration. The court's inherent jurisdiction in such matters did not constitute an unjustifiable interference with the appellants' status as parents or their rights under Article 8.

Fundamental to the appellants' case was the view that there are some decisions that should remain within parental authority unless there is a sufficient reason for their choice to be overridden. There may be reasonable disagreement over what is best for a child, and where this does not involve an intractable dispute between medical professionals and parents, parents should decide what is best. Without some threshold test for court involvement, all parental decisions would otherwise be vulnerable to court interference. At its heart, the Charlie Gard case is about more than which test applies in medical decisions about children; it goes directly to the question of where the boundary between private, family decisions and those in which the court may involve itself lies. The public reaction to the case reflected this, and demonstrated that many consider it right to leave the final say about a child's medical welfare to the

parents. The Court of Appeal and the Supreme Court disagreed. Both courts were clear that neither constitutional principles nor the ECHR prevented them from retaining decision making authority where the welfare of a child is at issue, and the European Court of Human Rights took the view that the margin of appreciation permitted this stance.

The introduction of a 'significant harm' threshold of the kind proposed would have been problematic. While arguably the court's power to intervene ought to be limited (a normative question for another paper), the threshold proposed was understandably rejected. The effect would have been to leave it to the court to determine whether the actions of the parents would cause 'significant harm'. This will often be subjective, influenced by the person's culture, religious beliefs, and social matrix and will be difficult to apply in medical cases (despite being applied in local authority care cases). The likely effect of adopting this threshold would therefore be that the inquiry would descend into a discussion of what is meant by 'harm' and how much of it is necessary to be 'significant' in a medical context. While the same considerations apply in the context of a 'best interests' assessment, the latter provides a well-established analytical framework which has developed over decades and allows harm to be considered within a wider context of other considerations.

Re-framing the analysis to include a presumption of parental authority unless rebutted by serious harm would also result in the parent's authority being subjected to direct evaluation by the court, which would be called upon to scrutinise their reasoning before overtly overriding it, if it is not accepted. This would arguably challenge the authority of the parents more directly than under the 'best interests' approach, where although parents' views are given considerable weight, they remain just one of many important factors that must be taken into account when determining a child's interests.

In fact, as argued by counsel, the threshold need not have been significant harm (though reading it across from the Children Act would have been coherent), but this does not reduce the validity of the appellants' point that there arguably should be some limit on when the Court can intervene in parental decision making.

Counsel for GOSH offered a useful response in arguing that were such a threshold for intervention to exist, it would create a zone of decisions into which the court could not intrude to protect some of the most vulnerable in society, until a sufficient risk of harm had emerged. It was argued that it is more appropriate to regard every case where the welfare of a child is engaged as justiciable. The court would remain free to decline to intervene in trivial matters (protecting a *de minimis* level of unchallenged parental authority) while retaining authority in the space between triviality and risk of significant harm, which the appellants would have denied it. The Supreme Court could be seen to have tacitly approved this view in affirming its authority to determine any matter engaging a child's welfare. Some deeper consideration of *why* this should be the boundary would have been welcome, because despite the objections to the proposed threshold, counsel raised legitimate concerns about the courts having

too much power to interfere in decisions that might be thought to rightly rest with parents.