

# Reflections on Charlie Gard and the Best Interests Standard From Both Sides of the Atlantic Ocean

Lainie Friedman Ross, MD, PhD

## abstract

Charlie Gard (August 4, 2016, to July 28, 2017) was an infant in the United Kingdom who was diagnosed with an encephalopathic form of mitochondrial DNA depletion syndrome caused by a mutation in the RRM2B gene. Charlie's parents raised £1.3 million (~\$1.6 million US) on a crowdfunding platform to travel to New York to pursue experimental nucleoside bypass treatment, which was being used to treat a myopathic form of mitochondrial DNA depletion syndrome caused by mutations in a different gene (TK2). The case made international headlines about what was in Charlie's best interest. In the medical ethics community, it raised the question of whether best interest serves as a guidance principle (a principle that provides substantive directions as to how decisions are to be made), an intervention principle (a principle specifying the conditions under which third parties are to intervene), both guidance and intervention, or neither. I show that the United Kingdom uses best interest as both guidance and intervention, and the United States uses best interest for neither. This explains why the decision to withdraw the ventilator without attempting nucleoside bypass treatment was the correct decision in the United Kingdom and why the opposite conclusion would have been reached in the United States.

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Dr Ross conceptualized and designed the study, drafted the initial manuscript, and approved the final manuscript as submitted.

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Charlie Gard was born on August 4, 2016 in the United Kingdom. He appeared healthy at birth, but within months, his parents noticed symptoms of muscle weakness and failure to thrive. By the time an extensive work-up identified the cause, an encephalopathic form of mitochondrial DNA depletion syndrome (MDDS) caused by a mutation in the RRM2B gene, Charlie was already paralyzed and on a ventilator. There were no animal models for MDDS caused by mutations in the RRM2B gene, no clinical trials underway, and no established treatments. His parents, however, had done their own research and were in contact with a mitochondrial expert at Columbia University Medical Center (CUMC) in New York, Dr Michio Hirano, who was investigating the use of nucleoside bypass treatment (NBT) to treat MDDS caused by mutation in the TK2 gene, a myopathic form of MDDS (which does not affect the brain). NBT has been shown to be effective in animal models with TK2.<sup>1</sup> Arturito Estopinan is a young boy with MDDS caused by a mutation in the TK2 gene who provides some anecdotal evidence that the treatment may be effective.<sup>2</sup> A clinical trial for MDDS patients with mutations in the TK2 gene was underway, although no results would be available for several years.<sup>3</sup>

After the request of Charlie's parents, the doctors at Great Ormond Street Hospital (GOSH) (London, United Kingdom) contacted Hirano and were starting to seek special approval to use NBT,<sup>4</sup> despite concerns that the treatment would not cross the blood-brain barrier. However, a repeat EEG on January 10, 2017, showed frequent electrical seizures, at which time all of the doctors at GOSH decided that further treatment would be "futile and would only prolong Charlie's suffering."<sup>4</sup> Although the doctors thought that withdrawal of treatment was in his

best interest, his parents argued that it was in his best interest to be transferred to CUMC to receive the experimental NBT. They raised £1.3 million on a crowdfunding page to travel to the United States to pursue this treatment.<sup>5</sup> The case was litigated in multiple UK courts and the European Court of Human Rights. The case made international headlines about what was in Charlie's best interest. In the medical ethics community, it raised the question of whether best interest serves as a guidance principle (a principle that provides substantive directions as to how decisions are to be made), an intervention principle (a principle specifying the conditions under which third parties are to intervene), both guidance and intervention, or neither.

### THE BEST INTEREST STANDARD AS INTERVENTION PRINCIPLE

In the last 2 centuries, the best interest of the child standard was adopted as an intervention principle to guide custody determinations between parents. It was considered more neutral than the Roman standard based on presumed paternal property rights or the later standard based on presumed maternal rights under the "tender years" doctrine.<sup>6,7</sup> However, it came under critical evaluation in the late 20th century for being "indeterminate and speculative" by the American legal scholar Robert Mnookin, who stated that "even if accurate predictions were possible in more cases, our society today lacks any clear-cut consensus about the values to be used in determining what is "best" or "least detrimental,"<sup>8</sup> the latter phrase adopted from Goldstein et al.<sup>9</sup> Goldstein et al<sup>10</sup> proposed guidelines for addressing the best interests of children in custody and placement situation which rested on 2 convictions: (1) the child's need for continuity of care by autonomous

parents to raise their children according to their own values, free of state interference; and (2) that the child's well-being must be determinative once justification for state intervention has been established.<sup>9,10</sup> That is, the state, not parents, are held to a best interest standard.<sup>9-11</sup>

In the United Kingdom, child custody disputes also employed the best interest standard as codified in the Guardianship of Minors Act 1971: "the court, in deciding that question, shall regard the welfare of the minor as the first and foremost consideration..."<sup>12</sup> This was further solidified with the passage of the Children Act 1989 in which Section 1(1) requires "that when a court determines any question with respect to the upbringing of a child, the child's welfare shall be the court's paramount consideration."<sup>13</sup> And yet, several British legal theorists, citing Mnookin, also criticized this principle for its indeterminacy and subjectivity.<sup>14,15</sup>

Mnookin's criticisms have been echoed and expanded by other theorists who argue that the best interest standard is too vague and too individualistic.<sup>16-19</sup> This has led to consideration of alternative intervention principles, particularly outside of the custody context, as explored below.

### BEST INTEREST AS GUIDANCE PRINCIPLE

In contrast with the use of the best interest standard as an intervention principle for custody disputes, the best interest standard was incorporated into 20th century medical ethics as a guidance principle for proxy decision makers. Beauchamp and Childress first used the best interest principle in the third edition (1983) of *Principles of Biomedical Ethics*: "Long before autonomy and privacy was applied to incompetents or minors, the

responsibility of parents toward their children was legally defined as the responsibility to act in the best interests of those children...<sup>20</sup>

Similarly, in *Deciding for Others: The Ethics of Surrogate Decision Making* (1989), Buchanan and Brock<sup>21</sup> argued that parents are the presumed decision makers for their minor children and they should be guided by the best interest principle. The use of best interest as a guidance principle has also become the standard in national professional organizations and international policy statements.<sup>22-29</sup>

### BEST INTEREST NOT TO BE TAKEN LITERALLY AS GUIDANCE

Despite claims that parents are held to a best interest guidance standard, many theorists argue for greater parental discretion than best interest permits. Beauchamp and Childress argued that parents should be guided by the best interest standard, but “the state should not interfere except in extreme circumstances in which the state and the parents disagree about some decision with potentially serious consequences for the child.”<sup>20</sup> Goldstein et al<sup>10</sup> also asserted the need to respect broad parental discretion: “when death is not a likely consequence of exercising a medical choice, there would be no justification for governmental intervention.”<sup>10</sup> Buchanan and Brock<sup>21</sup> were also explicit that failure to act in a child’s best interest was not justification for intervention. Rather they suggested it should be viewed as an aspirational goal and not a regulative ideal:

So long as the family’s choice of a particular treatment falls within the range of medically sound options, physicians should not insist that the particular option they favor be employed, nor should they seek intervention by a hospital ethics committee or other institutional or government agencies to challenge the family’s decision.<sup>21</sup>

### WHAT STANDARD THEN FOR INTERVENTION?

If parents are not literally held to a best interest standard, then when should the state intervene? The most popular intervention principle is the harm principle as explicated by Doug Diekema.<sup>30,31</sup> This is based on John Stuart Mill’s argument that “The only purpose for which power can rightfully be exercised over any member of a civilized community, against his will, is to prevent harm to others.”<sup>32</sup> Diekema argues that intervention can be justified in two situations, both of which fall under the harm principle. First, under the *parens patriae* doctrine, states are empowered “to protect and care for those who cannot care for themselves and may intervene when there is evidence that parental actions or decisions are likely to harm a child.”<sup>31</sup> Second, states may intervene to protect the health of the population.<sup>31</sup>

There are 2 separate criticisms of the harm principle. First, harm is one reason to intervene but not the sole reason. For example, Buchanan and Brock<sup>21</sup> offer 3 types of conditions that rebut the presumptive authority of parents.<sup>21</sup> The first type includes conditions that disqualify parents from the role of surrogate decision maker (eg, abuse or neglect, parental decisional incompetence). The second type specifies classes of cases that deserve special scrutiny, and here Buchanan and Brock<sup>21</sup> consider the child as tissue or organ donor for a sibling. The third type of case focuses on decisions that fall outside of the range of medically sound alternatives.

Second, Diekema limits intervention to state intervention.<sup>30,31</sup> Although the state must intervene when a child is placed at risk for serious harm, Buchanan and Brock<sup>21</sup> maintain that there may be other agents or institutions (eg, institutional ethics committees) that can intervene for other reasons.

### GUIDANCE AND INTERVENTION PRINCIPLES IN MEDICAL GUIDELINES IN THE UNITED STATES AND UNITED KINGDOM

Despite criticisms of the best interest standard, and controversy over what roles best interest plays in pediatric decision making, pediatric guidelines in both the United States and the United Kingdom assert that decision making should be held to the “best interest of the child” standard. There are two significant differences. First, in the United Kingdom, the best interest standard is viewed as an objective determination. The British Medical Association asserts:

A best interests judgement is as objective a test as possible of what would be in the child’s actual best interests, taking into account all relevant factors. It is customary to assume that a person’s interests are usually best served by measures that offer the hope of prolonging life or preventing damage to health, but this is not always the case.<sup>28</sup>

Specifically when focused on end-of-life care in pediatrics, the Royal College of Pediatrics and Child Health explains:

The court has inherent jurisdiction to grant a Declaration making it lawful for healthcare professionals to withhold or withdraw LST [life-sustaining treatment] notwithstanding the absence of parental consent if this is deemed to be in a child’s best interests...

The court will conduct a balancing exercise in which all relevant factors are weighed. The court will assess the benefits and burdens of giving or not giving potential treatments and of maintaining or withdrawing certain forms of treatment to assess best interests.<sup>29</sup> [references omitted]

An objective best interest allows the state to intervene if the parents make a good decision but the state decides another decision is better. That is, the best interest standard serves as both guidance and intervention principles. As such, the courts can and must override a reasonable parental decision if there is an objectively better option.

This position was clearly articulated by Justice Nicholas Francis in his High Court of Justice Family Division Opinion regarding Charlie:

Some people may ask why the court has any function in this process, why can the parents not make this decision on their own? The answer is that, although the parents have parental responsibility, overriding control is vested in the court exercising its independent and *objective judgement in the child's best interests*.<sup>33</sup> [emphasis added]

Mnookin provides a scathing objection to a court determination of objective best interest standard:

Obviously, more than one outcome is possible for each course of judicial action, so the judge must assess the probability of various outcomes and evaluate the seriousness of possible benefits and harms associated with each. But even where a judge has substantial information about the child's past home life and the present alternatives, present-day knowledge about human behavior provides no basis for the kind of individualized predictions required by the best-interests standard. There are numerous competing theories of human behavior, based on radically different conceptions of the nature of man, and no consensus exists that any one is correct.<sup>8</sup>

The more subjective best interest standard adopted in the United States gives greater deference to the parents. Whereas the objective view supports overriding parents who make a good decision if the state can select a better decision, the subjective view acknowledges the indeterminacy of knowing what is best and shows greater deference to parental discretion. It also acknowledges that parents have legitimate moral obligations to people other than the patient (including other siblings and themselves).<sup>19,34</sup> The state does not intervene unless the parental decision falls below some threshold (the harm principle) or other conditions justifying intervention emerge.<sup>21</sup> Thus, in the United States, there is an area of parental discretion where parental

decisions are not "best" but are "good enough."<sup>35-38</sup>

The difference in the role of best interest between the United States and United Kingdom is best understood in the following 2 tables (Tables 1 and 2). In fact, lawyers for Charlie's parents argued that the appropriate threshold for intervention should be harm, but this was rejected by the UK Court of Appeal.<sup>39</sup>

A second difference between US and UK employment of the best interest standard is that in the United Kingdom, if a court rules that it is in the child's best interest to have treatment withdrawn, treatment is withdrawn. In the United States, if a family can find a doctor willing to treat, then the child is transferred.<sup>40</sup> (This is true even in Texas, the only US state that currently has legislation that would allow doctors to withdraw treatment over a family's objection on grounds that the treatment is "futile"<sup>41</sup>). So, had Charlie been in any US hospital, he would have been transferred to CUMC.

### CHARLIE'S BEST INTEREST

If my analysis of the differences in the best interest standard across the Atlantic Ocean is correct, then the UK and European courts made the right decision to override Charlie's parents once they deemed withdrawal was in Charlie's objective best interest. Two concerns leave me unsettled. First, why did Charlie's physicians not provide experimental NBT during the prolonged legal battle? The treatment is administered by mouth (or g-tube in this case) and has minimal side effects (diarrhea), which is easily addressed in an infant who already wears a diaper. If Charlie had been

provided with this treatment (even if at parental expense), we may have known at the time of the last legal battle whether it offered any prospect of direct benefit.

But maybe I am wrong. Maybe the doctors at GOSH were right to withhold an experimental treatment of which there was no physiologic reason to expect it to work and no animal model data to support moving forward. The late Harvard surgeon-in-chief, Francis Moore, in talking about therapeutic innovation discussed the dangers of succumbing to "desperate remedies" phenomenon:

We often read in the medical literature that some patient was so desperately ill that almost anything was welcome by the patient, the family and the physicians. This sort of hyperbolic "desperate remedies" pressure on physicians and patients (and on the reading public) should be looked on with skepticism. There must be some likelihood of success before the desperate remedy becomes more than a desperate search for an opportunity to try a new procedure awaiting trial.<sup>42</sup>

If hindsight provides any consolation, the decision by the GOSH doctors looks better because there still are no animal models and no therapeutic clinical trials for encephalopathic MDDS. Looking forward, some funding has been secured.<sup>43</sup>

My second concern is the lack of critical evaluation of Hirano's actions by his peers. Hirano told Judge Francis that there was an "11% to 56% chance of clinically meaningful improvement" in muscular function with the proposed treatment without having examined Charlie in person<sup>44</sup> and without reviewing Charlie's medical records, brain images, or other expert opinions before making his prediction.<sup>45</sup> Given that NBT does not cross the blood-brain barrier, the likelihood that it would effectively provide "meaningful improvement" of Charlie's symptoms was low to nil. At best, one could postulate that the actual chance of any improvement was unknown.

**TABLE 1** Guidance and Intervention Principles in the United Kingdom

Guidance (in Principle)	Best Interest
Intervention	Best interest

**TABLE 2** Guidance and Intervention Principles in the United States

Guidance (in Principle)	Best Interest
Guidance (in practice)	Good enough or “zone of parental discretion”
Intervention	Harm principle (and special circumstances that merit third-party consideration)

GOSH lawyers also criticized Hirano for not declaring earlier his “financial interest” in some of the drugs he wanted to prescribe.<sup>45</sup> Although Hirano claimed “As I disclosed in court on July 13, I have relinquished and have no financial interest in the treatment being developed for Charlie’s condition,”<sup>45</sup> the actual timeline is not clear cut. In an article published in *Neurology Genetics* in 2018, Hirano disclosed holding a patent for rare pediatric disease and orphan drug designations for deoxynucleoside therapy for MDDS including TK2 deficiency.<sup>46</sup> These potential ethical violations were mostly overlooked in the media hype surrounding desperate parents seeking desperate measures for a dying child.

Despite these ethical concerns, Charlie’s parents may have still requested that Hirano treat Charlie with NBT. However, the disclosures may have curbed the UK Court’s willingness to hear the appeal for reconsideration of treatment on the basis of new facts about likelihood of therapeutic utility.<sup>47</sup>

## DENOUEMENT

In July 2017, Dr Hirano traveled to the United Kingdom, examined Charlie, and claimed that a recent “MRI scan of Charlie’s muscle tissue...revealed that it is very unlikely that he would benefit from this treatment.”<sup>45</sup> Charlie’s parents accepted his pronouncement, withdrew their appeal, and Charlie was transferred to a hospice unit, where the ventilator was withdrawn. He died in his parents’ arms on July 28, 2017, a week short of his first birthday.

For UK ethicists and clinicians, the case exemplifies a process in which courts have final jurisdiction about what is in a child’s “objective” best interest: a determination in which best interest serves as both the guidance and intervention principle. For US ethicists and clinicians, the case represents a more fundamental challenge since parents are not held to a best interest standard for guidance nor for intervention. Alternative guidance and intervention principles need to be identified so that all stakeholders know the boundaries and expectations of parental decision-making autonomy.

## ABBREVIATIONS

CUMC: Columbia University Medical Center  
 GOSH: Great Ormond Street Hospital  
 MDDS: mitochondrial DNA depletion syndrome  
 NBT: nucleoside bypass treatment

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