Parents and Treatment Decision-making for Very Young Children at the End of Life

A Comparative Analysis

Jordan Buck

Abstract. It is commonly accepted that parents have the responsibility to make decisions regarding the medical treatment of their very young children. This remains so at the end of their child's life when the decision must be made to withdraw treatment or pursue further interventions. In practice, this responsibility is conditional on the parents acting in their child's best interests. When parents make treatment decisions which are deemed by healthcare professionals to be contrary to the child's best interests, disputes can arise which may require resolution by the courts if an agreement cannot be reached in partnership. Under its inherent jurisdiction, the court then determines the course of action to be taken. This assessment lacks sufficient normative grounding with no guiding principle, resulting in excessive flexibility which is not properly constrained.

Given the flexibility of best interests, an inquiry into how—if at all—the decision-making process can be improved may be beneficial. In that sense, this thesis introduces one possible improvement in the form of the application of human dignity in making decisions. It will do this by comparing the German law approach to determining the child's best interests, based largely on the *Grundgesetz*, with the English law approach developed through the common law. The German approach is guided by the principle of human dignity, which offers a strong principled basis not just for the decisions made but for the intervention in the parents' decision-making responsibilities. The thesis will therefore address the level of engagement with the

parents' views and responsibilities in the two jurisdictions and how the courts engage with them whilst discharging the fundamental duty to protect the child's interests. It will suggest that English law may benefit from closer engagement with human dignity using German law as a model, and it will lay the preparatory foundations for the PhD thesis to follow.

Parents and Treatment Decision-making for Very Young Children at the End of Life

A Comparative Analysis

Jordan Buck

a thesis submitted for the degree of

Master of Jurisprudence (MJur)

Durham Law School

University of Durham

Je weniger die Leute davon wissen, wie Würste und Gesetze gemacht werden, desto besser schlafen sie.

The less people know about how sausages and laws are made, the better they sleep.

OTTO VON BISMARCK

Table of Contents

Acknowledgements

Completion of this thesis would not have been possible without the invaluable contributions and support of some equally invaluable people.

I am indebted to my two supervisors, Dr Samantha Halliday and Professor Emma Cave, for their sagacity, honesty, and most definitely their patience. Their insightful comments on earlier drafts of this thesis have, doubtless, permitted me to appear far more intelligent than I am. In that respect, any remaining infelicities are entirely my own. I owe them immeasurable thanks not only for this, but for having kindly—perhaps erringly?—offered to do the same for my PhD. I should also like to thank Dr Barend van Leeuwen for his input and advice over the years.

I am grateful to the friends I have made in the PGR suite within Durham Law School. Some of them were new faces and others were those who had taught me during my undergraduate degree. Whilst they may no longer teach me, I continue to learn from them.

My greatest thanks go to my family: my parents Lynette and Craig, my sister Leanne, my grandparents, and my extended family. Their support, often from afar, has been unfailing, and their (eventual) understanding of my excuses for why I don't have a 'real job' has been reassuring. I love them, but perhaps do not say it much, because—like breathing—it's the most natural, unthinking thing I do. This thesis is a product of theirs as much as it is of mine, and ultimately it is dedicated to them.

Table of Abbreviations

BGB	*Bürgerliches Gesetzbuch* German Civil Code
BGH	*Bundesgerichtshof* German Federal Court of Justice
BVerfG(E)	*(Entscheidungen des) Bundesverfassungsgericht(s)* (Decisions of the) German Federal Constitutional Court
BVerfGG	*Gesetz über das Bundesverfassungsgericht* Act on the German Federal Constitutional Court
BVerwG(E)	*(Entscheidungen des) Bundesverwaltungsgericht(s)* (Decisions of the) German Federal Administrative Court
CJEU	Court of Justice of the European Union
ECHR	European Convention of Human Rights
ECtHR	European Court of Human Rights
GG	*Grundgesetz* German Basic Law (also known as the German Constitution)
HCP	Healthcare Professional
LG	*Landgericht* or *Landesgericht** German District Court (for each of the *Länder*)
UNCRC	United Nations Convention on the Rights of the Child
VG	*Verfassungsgerichtshof* German Regional Constitutional Court

All translations in this thesis are my own, unless otherwise stated.

* The terms *Landgericht* and *Landesgericht* have the same meaning. The inclusion or omission of the *es* is a grammatical feature which changes by German-speaking region. In Germany, *Landgericht* is the most frequently used variant. See <http://mediawiki.ids-mannheim.de/VarGra/index.php/Landesgericht_/_Landgericht>, last accessed 28 May 2021.

Table of Cases

England and Wales

A

A (Children) (Conjoined Twins: Surgical Separation), Re [2001] Fam 147
Agar Ellis, Re (1883) 24 ChD 317, 50 LT (ns) 161
Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67
An NHS Trust v MB [2006] EWHC 507 (Fam)

B

B (A Minor) (Wardship: Medical Treatment), Re [1981] 1 WLR 1421
B (A Minor) (Wardship: Sterilisation), Re [1987] 2 WLR 1213

C

Cambridge University Hospitals NHS Foundation Trust v Mother of E & Anor [2021] EWHC 126 (Fam)
Camden LBC v R (A Minor) (Blood Transfusion) [1993] 2 FLR 757
Chief Constable of the Hertfordshire Police v Van Colle [2008] UKHL 50
Curtis, Re (1859) 27 LJ (ns) Ch 458

D

D (A Minor) (Wardship: Sterilisation), Re [1976] Fam 185
De Manneville v De Manneville (1804) 10 Ves 52

E F

E (Residence: Imposition of Conditions), Re [1997] 2 FLR 638
EV (A Child), Re [2017] UKSC 15.
Ex parte Skinner (1824) 9 Moore CP 279
Fixsler & Anor v Manchester University NHS Foundation Trust & Anor [2021] EWCA Civ 1018
Fynn, Re (1848) 2 DeG & Sm 457

G H

I J

K

L M

O

P Q

R

S

T U V

W

X Y Z

Germany

Bundesverfassungsgericht

Bundesverwaltungsgericht

Bundesgerichtshof

Landgerichte

Verfassungsgerichtshöfe

Verwaltungsgerichte

VG Berlin, Urteil v. 11.12.1996 36 X 643.95

Amtsgerichte

AG Essen-Borbeck, Urteil v.18.09.2017—3 Ds /70 Js 654/16—252/17

United States of America

City of Boerne v Flores (1997) 521 US 507
DeBurgh v DeBurgh (1952) 39 Cal. 2d 858
Marbury v Madison (1803) 5 US (1 Cranch) 137

European Court of Human Rights

A v UK (1999) 27 EHRR 611
Anayo v Germany (2010) Application 20578/07
Belgian Linguistic (No. 2) (1968) 1 EHRR 252
Charles Gard & Others v The United Kingdom (2017) Application 39793/17
Lambert & Others v France (2015) Application 46043/14
McGonnell v United Kingdom [2000] ECHR 62

Court of Justice of the European Union

A v Veselības ministrija (C-243/19) OJ C 182 (27.05.2019)
Omega Spielhallen und Automatenaufstellungs-GmbH v Oberbürgermeisterin der Bundesstadt Bonn (C-36/02) [2004] ECR I-9609

International Tribunals (Nuremberg)

US Military Tribunal Nuremberg, judgment of 19 July 1947, in Trials of War Criminals Before the Nuremberg Military Tribunals, Vol. II

Table of Legislation

England and Wales

Children Act 1989

s 1(1)
s 3
s 4(1)(a)
s 31(2)(a)
s 33(3)
s 58

Children and Young Persons Act 1933

s 1(1)
s 1(2)(a)

Guardianship Act 1973

s 1(1)

Guardianship of Infants Act 1886

s 5

Guardianship of Infants Act 1925

s 1

Mental Capacity Act 2005

s 5

Access to Palliative Care and Treatment of Children HL Bill (2019-21) [13]

Germany

Grundgesetz der Bundesrepublik Deutschland (GG)

Art 1(1)
Art 1(2)
Art 2(1)
Art 4(1)
Art 6(1)
Art 6(2)(1)
Art 10(1)
Art 13(1)
Art 31(1)
Art 79(3)

Gesetz über das Bundesverfassungsgericht (BVerfGG)

§ 31(1)
§ 95(3)

Bürgerliches Gesetzbuch (BGB)

§ 31(1)
§ 95(3)
§ 1591
§ 1592(1)
§ 1625
§ 1626
§ 1631
§ 1666
§ 1686a 1(1)
§ 1687b
§ 1688
§ 1793

Strafgesetzbuch (StGB)

§ 211
§ 218
§ 222
§ 223
§ 230
§ 323

Sozialgesetzbuch (SGB)

§ 27

Gesetz zur Neuregelung des Rechts der elterlichen Sorge (SorgeRG)

§ 42

Gesetz über die Eingetragene Lebenspartnerschaft (LPartG)

§ 9

Gesetz über die Angelegenheiten der freiwilligen Gerichtsbarkeit (FGG)

§ 42

Kinder- und Jugendhilfegesetz (KJHG)

§ 24

Reichsgesetzblatt (RGBl)

RGBl. I S. 529, Das Gesetz zur Verhütung erbkranken Nachwuchses v. 14.07.1933

International

Constitución Española

Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights, as amended) (ECHR)

Declaration of Ottawa on the Right of the Child for Health Care (50th World Medical Assembly, Ottawa, 1998)

UNGA Convention on the Rights of the Child (20 November 1989) UNTS 1577

UNGA Universal Declaration of Human Rights (10 December 1948) UNGA Res 217

Chapter I

Introduction

Family likeness has often a deep sadness in it. Nature, that great tragic dramatist, knits us together by bone and muscle, and divides us by the subtler web of our brains; blends yearning and repulsion; and ties us by our heart-strings to the beings that jar us at every movement.

Mary Ann Evans (George Eliot)[1]

Making decisions regarding the medical treatment for very young children draws the notion that parents know their children best into question, with the issue finding itself at the confluence of law, ethics, medical science, and social attitudes towards parenting. Whereas normally parents are expected—in terms of both of obligation and supposition—to make decisions for their children during their upbringing, medical treatment decisions are one arena where the parents do not enjoy the freedom of choice that is natural in other aspects of parenting. Under ideal circumstances, the child's parents and the healthcare professionals will come to agree on the action to take 'over a period of time, as each party comes to better understand the other and the reality of the child's long-term prospects'.[2] The parents may even voluntarily forego making the decision themselves and defer to the healthcare professionals on the grounds that they believe the medical professionals better understand their child's condition and what must be done

1 MA Evans (G Eliot), *Adam Bede* (London, John Blackwood, 1859), ch IV p 55.

2 D Davies & C Mack, 'When parents say "more" and health care professionals say "enough"' (2015) 20 *Paediatr Child Health* 3, 135.

about it,[3] or to avoid feeling complicit in any decisions taken which result in the death of their child.[4] When intractable disputes render this impossible, decisions are taken by the courts[5] on the basis of what is adjudged to be in the child's best interests, which places the child's welfare at the centre of the concern as the 'paramount consideration' in any matters before the courts.[6] The courts have repeatedly reaffirmed their own authority to make treatment decisions for children where the parents and healthcare professionals are unable to find common ground,[7] with their role having been regarded as one of a 'final arbiter'[8] of the child's best interests.

Despite this, there remains no satisfactory consensus regarding the principles upon which the assessment of the child's best interests should be based. The consequence of this is a lack of certainty: the best interests assessment is infinitely flexible, with minimal constraints on how it should operate and no indication as to where the final decisional authority should lie.[9] Due to this flexibility, the best interests assessment

3 ibid. See also PG Black, AR Dress, S Derrington, & JD Lantos, 'Can a patient designate his doctor as his proxy decision-maker?' (2013) 131 *Pediatrics* 986.

4 FA Carnevale, P Canoe, R Cremer et al, 'Parental involvement in treatment decisions regarding their critically ill child: A comparative study of France and Quebec' (2007) 8 *Pediatr Crit Care Med* 337; AA Kon, 'The "window of opportunity": Helping parents make the most difficult decision they will ever face using an informed non-dissent model' (2009) 9 *American Journal of Bioethics* 55.

5 It is possible that the decision may be resolved by steps in between the original dispute and the courts. Mediation and involvement by clinical ethics committees to assist in making a decision may resolve the disagreement before litigation is necessary. This thesis nonetheless considers only those cases where the courts must become involved.

6 Children Act 1989, s 1(1).

7 C Auckland & I Goold, 'Parental rights, best interests and significant harms: who should have the final say over a child's medical care?' (2019) 78 *Cambridge Law Journal* 2, 287.

8 B van Leeuwen, 'Free movement of life? The interaction between the best interests test and the right to freely receive services in Tafida Raqeeb' (2020) *Public Law* 3, 498. See also *Kings College Hospital NHS Foundation Trust v Haastrup* [2018] 2 FLR 1028, [69]; *An NHS Trust v MB* [2006] EWHC 507 (Fam).

9 See, for example, C Dyer, 'Parents fail to overturn ruling not to resuscitate baby' (2005) 330 *BMJ* 985.

and the law governing treatment decisions for children is the subject of a 'substantial disjunction between what the legal position *is* and what many people believe it *ought* to be'.[10]

The discord between 'what the legal position *is* and what many people believe it *ought* to be' indicates that there is some significant absence of consensus, resulting in part from a lack of a strong, principled foundation to the best interests assessment. In the absence of a meaningful grounding in principle, some, such as Auckland and Goold, argue that the threshold for judicial intervention 'lacks sufficient justification' and does not have a 'sufficient normative basis'.[11] Goldstein proposes that the state is 'too crude an instrument to become an adequate substitute for parents'.[12] This thesis proposes that greater engagement with the principle of human dignity may provide both the justification and the normative basis that the law lacks. Indeed, given the wide-ranging social issues at play, there may be some need to recalibrate the understanding of what constitutes a 'sufficient normative basis' so as to respect not just the individual, but the family as a whole. Decisions grounded in the principle of human dignity may transpire to be adaptable, as the patient-centric approach requires, but will be constrained as necessary to guarantee legal consistency.

10 C Auckland & I Goold, 'Parental rights, best interests and significant harms: who should have the final say over a child's medical care?' (2019) 78 *Cambridge Law Journal* 2, 287 (emphasis added).

11 ibid. The Access to Palliative Care and Treatment of Children HL Bill (2019-21) [13] seeks to address some of this in relation to the child's best interests.

12 J Goldstein, 'Medical Care for the Child at Risk on State Supervision of Parental Autonomy' (1977) 86 *Yale Law Journal* 645, 650.

Aims of the thesis

This thesis exists primarily as a stepping stone to the PhD thesis which will follow. In that regard, it seeks to lay the foundations for a wider discussion of the role of human dignity in end-of-life medical treatment decisions by first examining it in the context of parents' responsibility to decide on treatment for their very young children. To do this, it will evaluate whether the current application of the best interests assessment impedes the making of treatment decisions for very young children and whether the law should seek to engage more profoundly with the principle of human dignity as used in the German courts. This is approached from the central idea that a family may be described in terms of its members—the parents and the children—but is better understood in the context of its relationship with the state and wider society. The state is not a member of the family: it is not a literal Big Brother[13] (nor should it attempt to be a figurative one) but it nonetheless retains some ability in strictly confined circumstances to influence family life when it falls below societal standards. A relationship such as this relies on a delicate balance being struck between individual familial autonomy on the one hand and the paternalism of state intervention on the other, with each of the two pursuing the same goal albeit by different, occasionally conflicting, means.

This balance and complexity of the resulting relationship are poorly understood because much of the discussion of this topic in the literature results from individual cases where judgments have already been rendered in favour of one side of the argument or the other. Neutral approaches are consequently few and far between given that case commentaries in this area inevitably involve some level of agreement or disagreement with the decision taken. In lacking the wider scope of a

13 As popularised by G Orwell, *Nineteen Eighty-Four* (Secker & Warburg, 1949).

comparative analysis, for example, the literature falls short when it comes to acknowledging that disagreements in these cases are often the product of a general misunderstanding of the law. This thesis seeks to provide a more holistic account of the law by setting the frameworks in England and Wales into the wider context of European and international consensus-based approaches. This will be achieved by using Germany as a comparator and by drawing on the United Nations Convention on the Rights of the Child (UNCRC).

As a secondary aim, this thesis seeks to offer an alternative means of approaching the issue of who should make treatment decisions. It will evaluate the difficulties in allocating the final decision-making authority and re-shape the debate from one of 'who decides?' to a more outcome-focused question of how decisions should be taken based upon principles. The purpose of this new approach is twofold. Primarily its purpose is addressing the semantic shortcomings of the 'who decides?' question. Supporting the decision-making authority of either the parents or the healthcare professionals is rarely mutually exclusive from agreeing with their point of view, and inevitably agreeing with their point of view may even be the sole reason for supporting their decision-making authority in the first place. In many cases, the question of 'who decides?' can be reformulated as 'with whom do we agree?' with no change in meaning. What results from this is an unnecessary and unhelpful partisan approach. Instead, the approach should be one of establishing the principles by which the decision should be reached *before* determining who should be deciding. The secondary purpose of the new approach this thesis advocates is to recentralise the discussion onto the child. By the very nature of these cases, the question of 'who decides?'—where 'the child' is clearly not a possible answer—inevitably shifts the focus away from the child at the crucial moment. In anticipation of this, questioning how these decisions should be taken repositions the child's

welfare as the crucial consideration, resulting in a more purposive and less adversarial resolution process.

To achieve these aims, the discussion of dignity in CHAPTER IV will consider how the approaches in English and German law diverge, and subsequently where the English law may fall short of the protections for individual rights available in its German counterpart. It will propose that an application of the principle of human dignity may help clarify the parents' position in the decision-making process under English law by offering a standard which would increase the accessibility of the existing best interests assessment and by providing a threshold for intervention which relies less on subjectivity and the personal values of the decision-maker. In that regard, engagement with the principle of human dignity may prove beneficial to the resolution of these matters under English law.

Germany as a comparator: fundamental rights and human dignity

Germany has been chosen as a comparator for this thesis because it is closely culturally related with England and Wales, with each sharing similar western European attitudes towards the law, society, and family life.[14] Each has incorporated human rights through the European Convention on Human Rights (ECHR) which seeks to further the goals in the Universal Declaration of Human Rights (UDHR) of which the promotion and protection of human dignity forms the foundation. The two are also committed to the United Nations Convention on the Rights of the Child (UNCRC) which reiterates these rights and the foundational importance of dignity. Yet despite their joint commitments to these rights frameworks, the two jurisdictions diverge on their application of human dignity. Dignity is incorporated into English law indirectly through the Human Rights Act 1998, in that the 1998 Act implements the UDHR and ECHR, but it has nonetheless received relatively little attention Germany has placed it at the centre of its constitutional and legal order. These two different approaches will enable an examination of the role played by dignity, its effect on resolving matters concerning children's rights, and whether English law might benefit from greater involvement with it, using the German law approach as a model.

Beyond this, England and Wales is a common law jurisdiction with no codified constitution and no court charged specifically with resolving constitutional issues.[15] Individuals derive their rights mainly from the ECHR as implemented by the

14 See, eg, MA Glendon, *The Transformation of Family Law: State, Law, and Family in the United States and Western Europe* (University of Chicago Press, 1989).

15 The Supreme Court does hear cases of constitutional importance but its function is not limited to constitutional matters in the same way as the *Bundesverfassungsgericht*. Whether England and Wales or the wider United Kingdom have a constitution is a matter for debate beyond this thesis. See E Barendt, 'Is there a United Kingdom Constitution?' (1997) 17 *OJLS* 1.

Human Rights Act 1998 and from the common law.[16] On the other hand, Germany's civil law system is pervaded by legislative and judicial responses to its unique national history which saw considerable social instability as a result of an overwhelming imbalance in the power relationship between the state and its citizens.[17] Whilst the ECHR is also incorporated into German domestic law with the status of a federal statute,[18] the most significant source of rights is the *Grundgesetz*, the German Basic Law, which functions as the federal constitutional document. From the *Grundgesetz*, Germans derive many of the same rights which individuals in England and Wales enjoy, including the parental rights and responsibilities which enable parents to make decisions about their children.[19]

In 2020, Auckland and Goold set out their own comparative analysis of disputes over children's medical care.[20] One of the conclusions they reached was that

> 'to respect the value-plural nature of our society and its implications for the "best interests" approach, the courts ought to be more overt about the values to which they are committed, to allow open debate about these'.[21]

Whilst their comparative analysis drew on examples from England and Wales, the United States, and Australia, it did not discuss Germany. This thesis discusses

16 Since 1998, the common law has moved in a Convention-compliant direction. See, eg, *JD & Ors v East Berkshire Community Health & Ors* [2003] EWCA Civ 1151, [55]-[88]; *Chief Constable of the Hertfordshire Police v Van Colle* [2008] UKHL 50, [58].

17 See, eg, H König, M Kohlstruck, & A Wöll (eds), *Vergangenheitsbewältigung am Ende des zwanzigsten Jahrhunderts* (Springer, 1998); P Reichel, *Vergangenheitsbewältigung in Deutschland* (CH Beck, 2001).

18 *BVerfG*, Beschluss des Zweiten Senats vom 14.10.2004—2 BvR 1481/04, Rn 1-73.

19 Article 6 *Grundgesetz*.

20 C Auckland & I Goold, 'Resolving disagreement: a multi-jurisdictional comparative analysis of disputes about children's medical care' (2020) *Medical Law Review*.

21 ibid.

Germany because, where overtness about values and principles is concerned, the German courts' commitment to the principle of human dignity[22] acts as an example. In that regard, this thesis seeks to address the 'values to which [the courts] are committed' in England and Wales by proposing that the principle of human dignity be factored into this by drawing on its interpretation in Germany to provide some guidance as to how it may assist the understanding of children's best interests in English law.

One of the most significant facets of the employment of the principle of human dignity in Germany is the level of protection it is ascribed. Aside from Article 1, the *Grundgesetz* includes provisions which regulate the interactions between the state and individual citizens, with the interpretation of these provisions undertaken by the federal constitutional court, the *Bundesverfassungsgericht*.[23] Through the *Bundesverfassungsgericht*,[24] Germans are able to benefit from constitutional protection similar to that observed in the United States, where the US Supreme Court is able to strike down legislation as 'unconstitutional' given its powers of strong judicial review.[25] With 'the scope of its judgments and the sweep of its jurisdiction', the *Bundesverfassungsgericht* is viewed by some, such as Quint, as 'the

22 As required by Article 1(3) *Grundgesetz*.

23 The jurisdiction of the *Bundesverfassungsgericht* is set out in Article 93 *Grundgesetz* and the *Gesetz über das Bundesverfassungsgericht* (also known as the *Bundesverfassungsgerichtsgesetz* or *BVerfGG*).

24 § 95(3) *BVerfGG*: 'if the court grants [accepts] a constitutional complaint which challenges a law, that law shall be voided'; § 31(1) *BVerfGG*: 'the decisions of the *Bundesverfassungsgericht* are binding on the constitutional organs of the federal state and of the *Länder* [federal states], as well as on all courts and public authorities'. This binding authority is reliant on the cooperation of other public institutions. In 2018, the city of Wetzlar in Hesse refused to cooperate with a decision of the *Bundesverfassungsgericht*: see T Podolski, 'Stadt Wetzlar widersetzt sich dem BVerfG' *Legal Tribune Online* (26.03.2018) <www.lto.de/recht/hintergruende/h/bverfg-wetzlar-npd-versammlung-stadthalle-verbot-widersetzt/>, accessed 6 March 2021.

25 For a brief run-through of strong and weak judicial review, see, *eg*, M Tushnet, 'Weak-Form Judicial Review and "Core" Civil Liberties' (2006) 41 *Harv CR-CL L Rev* 1; *City of Boerne v Flores* (1997) 521 US 507, 529; *Marbury v Madison* (1803) 5 US (1 Cranch) 137, 177.

most extraordinarily powerful court of law the world has ever known'.[26] This sweeping power is instrumental to the court's enforcement of the constitutional principle of human dignity, which is regarded as the 'highest value in the system of fundamental rights'.[27] Enforcement of this principle is at the heart of Germany's inquisitorial system, assuming a much greater role in German law than it does in English law. More profound engagement with the principle in English law may prove beneficial to resolving disputes over children's best interests.

26 PE Quint, 'The Most Extraordinarily Powerful Court of Law the World Has Ever Known—Judicial Review in the United States and Germany' (2006) 65 *Maryland Law Review* 152, 153.

27 *BVerfGE* 35, 366 (376). See also *BVerfGE* 5, 85 (204); *BVerfGE* 45, 187 (227); *BVerfGE* 6, 32 (36); *BVerfGE* 54, 341 (357).

Thesis structure

Being that this thesis proceeds with comparison in mind, it is structured in two segments. The first concerns the domestic legal frameworks for children's and parents' rights in England and Wales and Germany; the second builds upon these foundations to compare the two approaches on the basis of implementing international rights protection laws and the principles used to apply them. The comparative chapter is not intended to compare all that is discussed in the two chapters that proceed it directly: indeed, those two alone may be sufficient to draw conclusions on the functional differences between England and Wales and Germany. Rather, the purpose of the comparative chapter is to use what has been learned from the analysis of the German law position to recalibrate the discussion of the English law position by evaluating key sticking points through a comparative lens.

II: Germany

The thesis begins with an analysis of the German law concerning children's best interests and the application of the principle of human dignity under the *Grundgesetz*. It characterises the latter as a universal ethical principle which came to be entrenched in the *Grundgesetz*[28] and interpreted widely in response to Germany's tumultuous history throughout the national socialist period. After contextualising the relationship between the individual and the state in relation to this, the chapter will consider how the parent-child-state relationship has evolved gradually to recognise the child as an individual rights-holder. As a consequence of this,

28 Article 1 *Grundgesetz*.

observation of the child's best interests has come to be recognised as a crucial obligation for parents.

Observation of the child's best interests will then be shown to be not only the duty of the parents, but of healthcare professionals and of the state through the necessity of protecting human dignity. In conjunction with the other constitutional rights under the *Grundgesetz* and historical consideration of the roles of doctors, dignity plays a significant role in matters concerning parental decisions over the medical treatment of their children. The chapter will consider the ramifications of this by way of reference to a case where the parents advocated for treatment in line with their religious beliefs.[29] Whilst the case does not concern end-of-life care—as did *Raqeeb*—it brings to light a crucial difference in how the parents' religious beliefs are weighed in the child's best interests assessment, with this difference arising predominantly from fundamental rights and the protection of human dignity under the *Grundgesetz*. The chapter will consider the implications of the German government's recent proposals to incorporate the child's best interests within the remit of Article 6 *Grundgesetz* and how this may impact on the parents' involvement in decision-making. Finally, it will consider arguments against the parents' authority to make medical treatment decisions for their children entirely.

III: England and Wales

Chapter III will be structured similarly to Chapter II, beginning with a historical overview of the development of parental responsibilities, children's rights, and best interests in England and Wales. It will highlight the progress that has been made in

29 *LG* Köln, Urteil v. 07.05.2012 – 151 Ns 169/11.

recognising children's best interests[30] but will concede that issues remain which may be taken to impede the proper functioning of the best interests assessment for children. In light of these challenges, Chapter III will consider the challenges that have been brought to modify the process by which decisions are made for very young children. Largely, the chapter will focus on the significant harm test, found elsewhere in child law[31] and popularised following the *Gard* litigation.[32] In practice, the significant harm test would not solve the issues the law faces. This will be shown through a practical application of the significant harm test to two landmark judgments where one child's parents demanded continued treatment and the others refused it.

Having established that the significant harm test would be an inappropriate solution to the issues the law faces, the chapter will discuss the role that dignity can play by evaluating the judgment in *Raqeeb*[33] in 2016 and the subsequent *Fixsler* case. It will show that dignity's role up to this point has been quite minimal, and that greater engagement with the principle may facilitate greater consistency and understanding when it comes to children's best interests.

Chapter III will also provide the basis for a discussion of the paramountcy principle[34] which will be continued in Chapter IV.

30 Specifically, it will focus on the law resulting from the Children Act 1989.

31 Children Act 1989, s 31(2)(a).

32 *Great Ormond Street Hospital v Gard & Others* [2017] EWHC 1909 (Fam). *Gard* was the real driving force behind calls to implement a significant harm threshold, largely because of its increased prominence in the public eye and media.

33 *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin), [2019] EWHC 2530 (Fam).

34 Children Act 1989, s 1(1).

IV: Comparative analysis

Using what has been discussed in the chapters on England and Wales and Germany as a foundation, CHAPTER IV will focus on the implementation and application of the values shared between the two jurisdictions. In this respect, the United Nations Convention on the Rights of the Child (UNCRC)[35] will form a large part of the comparative discussion, facilitating an evaluation of how England and Wales and Germany implement and observe their international legal obligations to protect children's rights, including the recent legislative movements in Germany to entrench the UNCRC within the remit of Article 6 *Grundgesetz*. It will be seen that implementing and enacting the UNCRC relies heavily on pre-existing domestic legal frameworks. Germany has its 'inviolable'[36] constitutional rights under the *Grundgesetz* which, arguably, already provide sufficient protection; England and Wales has its long-established lineage of common law decisions and the paramountcy principle which, *prima facie*, appears to offer more protection to children's rights than the primary consideration principle under the UNCRC. CHAPTER IV will also consider the role played by human dignity, which in Germany is an inviolable constitutional principle but has received little to no meaningful engagement in England and Wales.

35 United Nations Convention on the Rights of the Child (1989) A/RES/44/25.

36 Rights under the *Grundgesetz* are generally regarded as 'inviolable'; this is specifically stated in Articles 1, 2, 4, 10, & 13. However, Article 1, concerning the protection of human dignity, describes human dignity as *unantastbar*. In the other Articles, *unverletzlich* is used instead. Arguably, *unantastbar* necessitates an absolute level of protection for human dignity, which reflects the importance and centrality of human dignity as the inviolable foundation of all the rights which follow. The rights described as *unverletzlich* remain fundamental but are framed as permitting some degree of interference when necessary, much like the principle of proportionality under the ECHR.

Chapter II

German state oversight of parents and constitutional rights

Die Erziehung der Kinder ist eine Uraufgabe, eine von
Gott den Eltern auferlegte Pflicht, ist ihr ureigenstes Recht.

Franz Josef Strauß[1]

Introduction

Few nations have undergone changes throughout history as quickly and significantly as Germany. The modern *Bundesrepublik* is the result of tumultuous shifts across the political spectrum throughout the 21st century from fascism to communism and then to democracy. Consequently, its current political climate is uniquely one set against the backdrop of a national history that, far from being extolled like some other nations', is sworn never to be repeated, with the *nie wieder* ('never again') sentiments, in particular *nie wieder Krieg*,[2] having echoed throughout Germany since the end of the First and Second World Wars. This attitude pervades even the *Grundgesetz*, Germany's Basic Law or constitutional document,[3] where the *Ewigkeitsklausel* ('eternity' or 'entrenched clause') expressly prohibits any

1 FJ Strauß in *Bayernkurier* (09.07.1977).

2 The famous lithographic work by Käthe Kollwitz, created in 1924 and used throughout the 20th century as an anti-war peace movement poster, particularly in the 1970s and 1980s.

3 When adopted, the *Grundgesetz* was not formally referred to as a constitution, instead being intended as a provisional document to serve until Germany's reunification. It is now commonly accepted as having assumed that role: *BVerfG*, 2 BvE 2/08 v. 30.06.2009, [218]. See also reference to the *Grundgesetz* as the *'deutsche Verfassung'* ('German constitution') in *BVerfG*, 2 BvR 1481/04 v. 14.10.2004, [33], [35]; and *'unsere bundesstaatliche Verfassung'* ('our federal constitution') in *BVerfGE* 16, 64 (79).

amendments which would contravene the principles of German democracy or erode the basic rights of German citizens.[4] Contemplations of this history[5] inform and constrain many aspects of German life, not least the political and legal elements. As such, an understanding of this history and of how the state determined what life had value—who was allowed to live and who was to die—is necessary to contextualise how the relationship between the individual and the state has been shaped. This context is then necessary to appreciate the foundations of parental rights in Germany. Political reservations over Germany's problematic history can, incidentally, stunt what may be regarded as the 'natural' development of the law. One of the most profound examples of this is the question of euthanasia, where members of the *Ethikrat*—the German National Ethics Council—who have previously positioned themselves in favour of liberalising the laws concerning euthanasia have nonetheless voted against such a move for political reasons.[6] Consideration of these socio-political and cultural difficulties will frame the individual-based approach that is taken in Germany and will provide an explanation for the delineation of the parent-child-state relationship that will be explored later on in the chapter.

Direct comparisons with the discussion in the next chapter may then be drawn from an examination of the history of German parental rights and of how the parent-child relationship evolved from one of the child being entirely subservient to the father to an arrangement whereby the parents, in tandem, 'serve' the child. The

4 Article 79(3) *Grundgesetz*.

5 The history of the East German (DDR) regime under the *Sozialistische Einheitspartei Deutschlands* (SED) is also responsible for many of modern-day Germany's political approaches, for reasons good and bad. It reinforced the reaction to the Nazi period and *Gleichschaltung*, with the addition of the human rights violations perpetrated by the *Ministerium für Staatssicherheit* (commonly known as the *Stasi*) warning against excessive state power and intrusion into individual private life.

6 Deutscher Ethikrat, *Selbstbestimmung und Fürsorge am Lebensende* (Berlin, 2006).

chapter will chart the course of this change with reference to three milestone developments in the law, beginning with the concept of *väterliche Gewalt*, or 'paternal power', which gradually transitioned into the shared *elterliche Gewalt* or 'parental power'. Once state intervention and oversight became a key aspect in the relationship, *elterliche Gewalt* transformed ultimately into *elterliche Sorge*, or 'parental responsibility'. Each developmental shift will be linked to changing attitudes regarding the status of children in society, their respective individual rights, and the level of oversight required from public authorities to guarantee these rights not just for children as young, vulnerable people, but as members of the German society and holders of fundamental rights under the *Grundgesetz*.

After having delineated the parent-child-state relationship, the chapter will explore how this triadic approach impacts the parents' responsibilities to provide a suitable upbringing and to make decisions in their child's best interests in the context of medical interventions. Here, the rights of the child, the constitutional principle of human dignity, and the prerequisites for state intervention often coincide with the healthcare professionals' professional obligations and provide greater remit, grounded in inalienable legal principle, for the overriding of parental decisions and wishes. However, there is a relative paucity of landmark cases in Germany compared to England and Wales. This may well be because disputes are resolved in hospitals before the need for litigation is necessary; it may be that the doctors acquiesce and continue to treat the child or transfer the child elsewhere for treatment. What is certain, however, is that the family courts in Germany are not as accessible to public observation as they are in England and Wales.[7] Consequently, it is more difficult to chart a jurisprudential chronology. Much of the discussion of parental rights in Germany must be based upon the law as written rather than the

7 J Salzgeber & S Warning-Peltz, 'Hearing the voice of the child: Current practice in family courts in Germany' (2019) 57 *Family Court Review* 3, 387.

law as interpreted, though the processes by which decisions are made in Germany share a considerable degree of similarity with England and Wales. There are, inevitably, however, differences between the two.

The first is the possibility that parents' religious views may be disregarded in instances where in England and Wales this might not be the case. The second is the positioning of Germany's threshold for state intervention as a proportionality exercise to balance the child's and the parents' constitutional rights. In practice, this appears to share some similarities with the proposed 'significant' harm test in England and Wales following cases such as *Gard*. These differences reflect the delicate balance that German courts must strike between different rights guaranteed by the *Grundgesetz*, which are designed to coexist but may incidentally compete with one another. As such, the chapter will grapple with the thin line that separates the autonomous choice of parents from the individual rights of the child who is often the subject of those choices. [8] It will conclude that parental responsibility and children's rights are to be regarded as symbiotic, with any difficulties or challenges being the result of misinterpretation rather than issues with the rights themselves, and so the crucial differences are practical rather than doctrinal. Treading this thin line is a delicate process but one which may nonetheless be assisted by engagement with human dignity.

This discussion will feed into a more general debate on the regulation of the private sphere through challenges to the parents' legitimacy and ability to make treatment decisions in their children's best interests. Some support has mounted for schools of thought which claim the emotional burdens faced by parents and their lack of

8 'The central idea that underlies the concept of autonomy is indicated by the etymology of the term: *autos* (self) and *nomos* (rule or law)'—G Dworkin, *The Theory and Practice of Autonomy* (CUP, 1988), p 108.

expert medical knowledge mean that they are not the best placed to make these crucial decisions. The chapter will reject assertions of this kind, arguing instead that the parents *must* be involved in the decision-making process not just as a matter of their constitutionally guaranteed right to parent but as part of their role as arbiters of the child's best interests.

Historical imbalances between the individual and the state

'Millionen Tote mahnen': the weight of Germany's past in the present

The modern German provision of rights and interactions in the medical setting are influenced heavily by a turbulent past. Germany's defeat in two World Wars, its descent into fascist nationalism, and its subsequent division and reunification in the dying embers of the 20th century left a country no longer at war with the world, but in conflict with itself. The fall of the Berlin Wall paved the way for a unified federal republic built upon the common desire that the horrors of the past, particularly the Nazi regime, never be repeated. But this common desire presented the common problem of coming to terms with that past. *Die Vergangenheitsbewältigung*, as it is known in German, exists not just as a cultural phenomenon[9] but as an academic debate and political obstacle. Working through these troubles of the past has become for many a problematic concomitant of the German identity, leading some to struggle with reconciling their beliefs and values with what had happened in the name of Germany previously.[10]

At the heart of these problematic historical considerations is the Nazi regime, particularly its invasion into private family life, its abusive treatment of children, and its twisting of medical science to propagandise the systematic killing of those it considered inferior. This continues to have profound implications on end-of-life care, where the Holocaust and the legacy of the 'Nazi doctors'[11] plays 'an enormous

9 See, eg, B Schlink, *Der Vorleser* (Diogenes, Zürich, 1995).

10 P Rutschmann, 'Vergangenheitsbewältigung: Historikerstreit and the Notion of Continued Responsibility' (2011) 25 *New German Review: A Journal of Germanic Studies* 1.

11 F Kudlien, *Ärzte im Nationalsozialismus* (Kiepenheuer & Witch, 1985); US Military Tribunal Nuremberg, judgment of 19 July 1947, in Trials of War Criminals Before the Nuremberg Military Tribunals, Vol. II (*United States of America v. Karl Brandt, et al.*).

argumentative role'.[12] The role of doctors in patient deaths remains a concern, with even the *Ethikrat* having gone as far as classifying the mass murder under the Nazi regime as *kriminelle Euthanasie*, or 'criminal' euthanasia, to distance modern conceptions of deaths in the medical setting from the killings perpetrated by the Nazis.[13] The modern German approach, based heavily on the principle of human dignity and the acknowledgement of individual value, favours the approach of *Sterbehilfe* ('assistance in dying'). This is not active assistance, but the provision of care and support during the dying phase.[14] *Sterbehilfe* is often used in conjunction with *Sterbebegleitung*, the act of providing care and support to the patient during the dying phase without actively assisting that death. This means that agreements between a child's parents and the treating healthcare professionals not to treat the child can be permissible. Nevertheless, the weight of Germany's past means that these patient deaths continue to be looked upon reservedly.

Responsibility for modern-day conservative outlooks upon the involvement of healthcare professionals in a patient's death can, in part, be traced to the work of German professors Karl Binding and Alfred Hoche,[15] who justified the killing of individuals designated as having *lebensunwertes Leben*, or a 'life unworthy of life', as being compassionate and consistent with medical ethics. Part of this ethical justification was the euphemistic concept of *Gnadentod*, or 'merciful death', which

12 S Schicktanz et al, 'The Cultural Context of End-of-Life Ethics: A Comparison of Germany and Israel' (2010) 19 *Cambridge Quarterly Healthcare Ethics* 381; HW Schmuhl, 'Nationalsozialismus als Argument im aktuellen Medizinethik-Diskurs. Eine Zwischenbilanz' in A Frewer & C Eickhoff (eds), *Euthanasie und die aktuelle Sterbehilfe-Debatte. Die historischen Hintergründe medizinischer Ethik* (Frankfurt-am-Main, 2000), pp 385-407.

13 Deutscher Ethikrat (n 6), p 44. See also GJ Annas & MA Grodin, *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation* (OUP, 1992); MR Marrus, 'The Nuremberg Doctors Trial in Historical Context' (1999) 73 *Bulletin of the History of Medicine* 1, 106–123.

14 Deutscher Ethikrat (n 6), p 45.

15 K Binding & A Hoche, *Die Freigabe der Vernichtung lebensunwerten Lebens* (Leipzig, Meiner Verlag, 1922).

implied that the killing of these individuals deemed unworthy of living was a benevolent act consistent with ethical medical practice. Binding and Hoche's work and the concept of *Gnadentod* were instrumental to the attempts by the Nazi regime to legitimise *Aktion T4*,[16] the mass extermination of those whom the state had determined to be unworthy of life. *Aktion T4* was instigated by Hitler himself, writing that *Reichsleiter* Philipp Bouhler and Dr Karl Brandt—the first defendant in the Nuremberg Doctors' trial—were empowered euphemistically

> 'to extend the authority to named physicians to grant a merciful death to those considered incurably ill following a careful assessment of their condition'.[17]

This practice also saw the creation of the Reich Committee for the Scientific Registering of Serious Hereditary and Congenital Illnesses which, under a 1933 law, registered all children born with hereditary conditions.[18] Children registered under this arrangement were invariably regarded as *Untermenschen*[19] or as those who lived a *lebensunwertes Leben*. As a result of this classification, parents were often coerced into agreeing for their children to be taken away, with authorities promising them that their children would be taken to specialist centres for higher quality medical

16 *Aktion Tiergartenstraße 4* ('the T4 program') was named after an address in Berlin that functioned as the headquarters for the euphemistically named *Gemeinnützige Stiftung für Heil- und Anstaltspflege* (the Charitable Foundation for Curative and Institutional Care). See G Sereny, *Into that Darkness: An Examination of Conscience* (New York, 1983), p 48.

17 *Order to Bouhler and Dr. [Karl] Brandt to increase the authority of physicians to perform euthanasia*, Nuremberg document PS-630, dated 1 September 1939, available at <http://nuremberg.law.harvard.edu/documents/2493-order-to-bouhler-and-dr?q=evidence:%22PS-630%22#p.1>.

18 RGBl. I S. 529, *Das Gesetz zur Verhütung erbkranken Nachwuchses v. 14.07.1933*. This law came into force on 1 January 1934.

19 This term and its racist connotations were adopted by Nazi propagandists around the same time as white supremacists in America. It is possible that the term was constructed as an opposite to Nietzsche's *Übermensch*.

treatment.[20] Instead, their children were killed by the state and the circumstances surrounding their deaths were fabricated to suggest a genuine medical justification for the death.[21] Gradually, the state increased the pressure it placed on parents, many of whom had begun to refuse consent to their children being taken away. Parents' refusals became all the more common when, despite attempts by the state to conceal the killings, it transpired that any charges against institutions to which children were sent to be killed were suppressed.[22] Faced with increasing public outcry as a result of sermons given by the Bishop of Münster, Cardinal von Galen,[23] the state responded by threatening parents with the loss of custody of all their children and with the possibility that they be conscripted for labour should they not comply.[24] Lothar Kreyssig, a judge in Brandenburg an der Havel, defied *Aktion T4* by challenging its legality and by making hundreds of disabled children wards of the court to prevent them from being removed from his jurisdiction.[25]

The ramifications of the state determining what life has value continue to be 'an inevitable concomitant of any political debate', particularly where human dignity is concerned.[26] Consequently, there is an 'intense suspicion of any liberalisation of the prohibition of killing on request among the disabled and their families',[27] and of deaths resulting from medical interventions. Even with individual members

20 Sereny (n 16), p 53.

21 RJ Lifton, The Nazi Doctors: Medical Killing and the Psychology of Genocide (New York, 2000), p 60.

22 This was done on the order of Hitler himself. See the testimony of Karl Brandt in US Military Tribunal Nuremberg, judgment of 19 July 1947, in Trials of War Criminals Before the Nuremberg Military Tribunals, Vol. II (*United States of America v. Karl Brandt, et al.*).

23 von Galen delivered a number of anti-Nazi sermons which were circulated throughout Germany by other members of the Church and via allied airdrops. See B Griech-Polelle, 'Image of a churchman-resister: Bishop von Galen, the euthanasia project and the sermons of summer 1941' (2001) 36 *Journal of Contemporary History* 1, 41.

24 Lifton (n 21), p 55.

25 See K Weiß, *Lothar Kreyssig: Prophet der Versöhnung* (Gerlingen Bleicher, 1998).

26 Lifton (n 21), p 55.

27 Deutscher Ethikrat (n 6), p 34.

expressing views in favour of a more liberalised legal approach, the *Ethikrat* has continued to 'support the recommendation that the prohibition of killing on request should be maintained' as a result of 'political consideration of German history of criminal euthanasia under the Nazi regime'.[28] In the same report, the *Ethikrat* also advocated a position of 'protection of life' as opposed to the more religiously-loaded and absolute connotations of the 'sanctity of life' principle.[29] Such a position reflects the positive duty imposed upon all state organs to protect life [30] and is more compatible with the ethos that 'the necessity of dying is an ineluctable fact'[31] and an individual event over which individual control is desirable. For this reason, the prevailing view in Germany is that suicide is protected by Art 2(1) *Grundgesetz* and that there is no obligation on individuals to remain alive if they do not wish to. Individual rights take priority over those of the state.[32] In response to questions over the position of healthcare professionals in this relationship, the *Ethikrat* has deferred to the *Bundesärztekammer* (German Medical Association), reiterating the professional position that 'it is not the duty of a doctor to collaborate in suicide'.[33] In fact, the inverse is true: the *Strafgesetzbuch* makes clear that there is a general obligation to render assistance to those in peril,[34] with this obligation incumbent on healthcare professionals and on the public.[35]

Schicktanz proposes that this institutional hesitance 'could be described as taking historical responsibility for the criminal euthanasia practised under the Nazi

28 ibid, p 88.
29 ibid.
30 Article 2 *Grundgesetz*.
31 Deutscher Ethikrat (n 6), p 88.
32 ibid.
33 Deutscher Ethikrat, Zur Regelung der Suizidbeihilfe in einer offenen Gesellschaft: Deutscher Ethikrat empfiehlt gesetzliche Stärkung der Suizidprävention (2014).
34 § 323c *StGB*.
35 *AG* Essen-Borbeck, Urteil vom 18.09.2017 — 3 Ds /70 Js 654/16 — 252/17.

regime'.[36] Indeed, the *Ethikrat* is not alone in considering the history of the Nazi regime to be a significant factor in law-making. In 2002, the German Parliament affirmed that the guarantee of human dignity under Article 1 *Grundgesetz*[37] and the principle of informed consent were 'justified as legal tools to impede any future events that are comparable to those that took place during the National Socialist regime'.[38] As a result, dignity has been positioned as the most significant pillar in the *Grundgesetz* and legal order.[39]

Historical approaches to children's rights and parental duty

Institutional concerns over excessive interference with individual life have pervaded the family sphere much in the same way as the medical sphere, though this has evolved from an original position of deference to paternal power to the modern position of respecting familial autonomy. Originally, the state was reluctant to involve itself in parenting and family affairs. The father, as the head of the family, exercised *patria potestas* decision-making powers separately from the state.[40] The state's position of minimising public interference with family affairs continues to be reflected in the *Grundgesetz* today, albeit subject to the necessary qualifications which empower the state to intervene where necessary for the welfare of the child.[41]

36 S Schicktanz et al, 'The Cultural Context of End-of-Life Ethics: A Comparison of Germany and Israel' (2010) 19 *Cambridge Quarterly Healthcare Ethics* 381.

37 Dignity applies to all humans in Germany and foetuses too. See *BVerfGE* 88, 203 (252).

38 Deutscher Bundestag, 'Schlussbericht der Enquete-Kommission "Recht und Ethik der modernen Medizin"' (14/9020, 14.05.2002).

39 Article 1 *Grundgesetz*. Dignity is the only protected interest designated as inviolable and unconditional.

40 A Duncker, *Gleichheit und Ungleichheit in der Ehe: persönliche Stellung von Frau und Mann im Recht der ehelichen Lebensgemeinschaft 1700-1914* (Cologne, Böhlau Verlag GmbH, 2003), p 1039.

41 See Article 6 *Grundgesetz*. This principle is also reflected in Article 8 European Convention on Human Rights (ECHR).

Väterliche Gewalt

In the 18th century, the father's control over the family became known as *väterliche Gewalt* (paternal authority) and, by the middle-19th century, came to be accepted as a central idea in German family life.[42] This idea was shared between many European countries [43] and was a 'comprehensive right to rule the family',[44] founded on a primitive conceptualisation of the positions held by the 'weaker' and 'stronger' in society. This belief was legitimised by the assertion that 'the man's rule over his wife is founded in nature'.[45] Whilst today, there is an obligation upon those holding stronger positions in society (eg, the parents) to protect the more vulnerable (eg, the children), historically the obligation was on the more vulnerable to depend and rely on the stronger.[46] As such, married women and their children were not true rights-holders. Instead, they derived benefits from the rights that the father held and chose to exercise in their interests. They were regarded as being 'one step lower than the man' and could only attain a similar status as them 'by making [themselves] the means of satisfaction of the man', deriving 'all her dignity only by doing it out of love for him'.[47] This is not the human dignity protected by the *Grundgesetz*, but it offers an interesting perspective on the inherent value of humans. Whereas the dignity protected by the *Grundgesetz* is inviolable and unconditional, the dignity of

42 H Willekens, 'Die Geschichte des Familienrechts in Deutschland seit 1794. Eine Interpretation aus vergleichender Perspektive' in S Meder (ed), *Frauenrecht und Rechtsgeschichte: die Rechtskämpfe der deutschen Frauenbewegung* (Cologne, Böhlau Verlag GmbH, 2006), pp 137-168. See also A Stoelzel, *Das Recht der väterlichen Gewalt in Preußen* (Berlin, Decker, 1874).

43 U Gerhard, 'Die Frau als Rechtsperson—oder: Wie verschieden sind die Geschlechter? Einblicke in die Jurisprudenz des 19. Jahrhunderts' in *Zeitschrift der Savigny-Stiftung für Rechtsgeschichte: Germanistiche Abteilung* (130th edn, 2013).

44 G Schiemann, 'Patria potestas' in H Cancik & H Schneider (eds), *Der neue Paly* (2000), p 402.

45 JG Fichte, 'Deduktion der Ehe' in JG Fichte (ed), *Grundlage des Naturrechts nach den Prinzipien der Wissenschaftslehre* (Leipzig, Christian Ernst Gabler, 1797), pp 298-338.

46 CFW von Gerber, *System des Deutschen Privatrechts* (2nd edn, 1850), p 496 § 222.

47 ibid.

the mother in the historical sense was conditional, derived from and subordinate to the father's authority.

As striking as the imbalance in the relationship and the position of strength held by men over their wives and children were, *väterliche Gewalt* was entrenched as the proper allocation of decision-making authority within the family. A father's power was such that it was commonly accepted that he could even sell his children in cases of dire financial circumstances.[48] Towards the end of the 19th century,[49] the equation of *väterliche Gewalt* with the Latin *patria potestas* began to be rejected as the arrangement came to be regarded as unsustainable in a developing society,[50] coinciding with a general trend in Europe towards ascribing greater rights to women and children. In light of this, the position changed from one of *väterliche Gewalt* (paternal authority) to *elterliche Gewalt* (parental authority).[51]

Elterliche Gewalt

The concept of *elterliche Gewalt*—that is, 'parental authority rather than 'paternal authority—was relatively short-lived, functioning more as a transition between *väterliche Gewalt* and *elterliche Sorge*. *Elterliche Gewalt* evolved as a result of growing understandings of child welfare and increased state involvement brought on by the new idea of state guardianship. In the beginning, the state's authority to remedy breaches of parental duties was derived not from the rights of the child, but as a

48 J Grimm, *Deutsche Rechtsaltertümer* (Reprint der 4. Aufl. 1899, Darmstadt, 1983), p 635.

49 E Holthöfer, 'Die Geschlechtsvormundschaft. Ein Überblick von der Antike bis ins 19. Jahrhundert' & DW Sabean, 'Allianzen und Listen: Geschlechtsvormundschaft im 18. und 19. Jahrhundert' in U Gerhard (ed), *Frauen in der Geschichte des Rechts: von der Frühen Neuzeit bis zur Gegenwart* (Munich, Beck, 1997), pp 390-451 & 452-459, respectively.

50 LR von Salis, 'Beitrag zur Geschichte der väterlichen Gewalt nach altfranzösischem Recht' in *Zeitschrift der Savigny-Stiftung für Rechtsgeschichte. Germanistische Abtheilung* (7th vol., 1887), pp 137–204.

51 BGBl 1979 I 42, das Gesetz zur Neuregelung des Rechts der elterlichen Sorge v. 24.07.1979.

'mere reflex' from its own duty—influenced by Christianity—to 'ensure the rearing of respectable and capable subjects'. [52] To that end, the early concept of 'guardianship' was conceived almost ironically: it was a safeguard of the state interest in the child, not of the child as an individual themselves. Nonetheless, this marked a significant departure from the previous attitude which reduced children to mere chattels and did not recognise them as individual rights-holders.

This changed in 1968, when the *Bundesverfassungsgericht* ruled that children are fundamental rights-holders because they are also beings worthy of dignity, the right to self-determination, and the other protections afforded to Germans under the *Grundgesetz*. [53] Attitudes towards the concept of *elterliche Gewalt* shifted further as additional reforms began to take place in the latter half of the 'century of the child', [54] with a government draft on modernising the parent-child-state relationship inviting lively debates in 1974. [55] Greater state oversight of the parent-child relationship and the child's stronger status as a rights-holder inevitably came into conflict with the concept of parental authority, which in 1976 the *Bundesgerichtshof* appreciated had come to be misunderstood as parental 'coercion'. [56]

Elterliche Sorge

In order to resolve this discrepancy, the *elterliche Gewalt* formulation of 'parental authority' was rephrased in law as *elterliche Sorge* ('parental responsibility') in 1979 [57]

52 D Schwab, 'Familienrecht' in D Willoweit (ed), *Rechtswissenschaft und Rechtsliteratur im 20. Jahrhundert* (CH Beck, 2007), p 302.

53 *BVerfGE* 24, 119 (144).

54 Schwab (n 52), p 304.

55 Deutscher Bundestag, 'Entwurf eines Gesetzes zur Neuregelung des Rechts der elterlichen Sorge' (Drucksache 7/2060, 02.05.74).

56 *BGHZ* 66, 337.

57 *BGBl* 1979 I 42 (*das Gesetz zur Neuregelung des Rechts der elterlichen Sorge* v. 24.07.1979); BT-Drs 8/2788, p 36; BGH, 14.03.1979 - IV ZR 98/78. Similarly, the GDR (East Germany) replaced *elterliche Gewalt* with *Erziehungsrechte* (rights of parents to bring up their children) in § 42 FGG.

before the new law regulating parental custody came into force in 1980.[58] With this, the transformation of parental rights was effectively complete. The parents' authority had now been reconstituted as responsibilities, with their rights as parents reframed as rights of defence against state interference.[59] Having previously been constructed as *Herrschaftsrechte* giving parents rights over children, they instead became viewed as *dienende Rechte*, or rights to serve the child.[60] The new relationship better recognised the principle that children are holders of fundamental rights, with some commentators viewing the child's basic rights to life and health as 'higher-ranking'[61] in that they required protection by the parents under the new *elterliche Sorge* approach. The state's involvement also adapted in line with this new perspective. Following the reunification of Germany in 1990, the state took on a positive duty to support families and promote children's' interests, such as by introducing laws which guaranteed subsidised kindergarten places. [62] The *Grundgesetz* continues to attach special protections to the rights of parents and their children.[63]

In line with its judgments that children are holders of basic rights, the *Bundesverfassungsgericht* has repeatedly emphasised the child's constitutional guarantee of parental care and upbringing and the subsequent obligation upon the

58 Gesetz zur Neuregelung des Rechts der elterlichen Sorge v. 18. 7. 1979 (BGBl. I S. 1061).

59 § 1625 *BGB*, paras 1-4.

60 R Nave-Herz (ed), Wandel und Kontinuität der Familie in der Bundesrepublik Deutschland (Oldenburg, De Gruyter, 1988), p 24.

61 W Eisenmenger & RJ Jox, 'Pädiatrische Palliativmedizin: Die juristische Sicht' in M Führer, A Duroux, & GD Borasio (eds), *„Können Sie denn gar nichts mehr für mein Kind tun?" Therapiezieländerung und Palliativmedizin in der Pädiatrie* (Stuttgart, Kohlhammer, 2006), p 52.

62 § 24 *Kinder- und Jugendhilfegesetz (KJHG)*. See also H Bertram, 'Money, time, and infrastructure as elements of a new German family policy' in B Holthus & H Bertram (eds), *Parental well-being: Satisfaction with work, family life, and family policy in German and Japan* (Iucidium Verlag, 2018) p 259.

63 *BVerfGE* 4, 52; *BVerfGE* 7, 320. See also the *SorgeFG*, which insulated the parent-child relationship from 'juridification': Schwab (n 42), p 305.

parents to provide it.[64] These guarantees have been derived from Article 2(1) *Grundgesetz* read in connection with Article 6(2)(1) to determine that the care and upbringing of children is the 'natural right' of the parents and also the primary duty incumbent upon them as parents.[65] Thus, the concept of parental responsibility under the *elterliche Sorge* conceptualisation has been shaped by the *Bundesverfassungsgericht* as being the product of the interaction between parental *rights* and parental *obligations*.[66] As such, it is regarded privately and publicly: the parents have duties to their children in a private familial sense, and they have duties in a wider public sense to protect children generally, for they are regarded as the most vulnerable people in need of protection in society.[67] The public element brings with it a number of interesting challenges concerning the delineation of the relationships between the parents, the children, and the state.

64 *BVerfGE* 133, 59, 73 ff, Rn 40 ff = JZ 2013, 460; *BVerfGE*, Beschluss des Ersten Senats v. 17.12.2013 – 1 BvL 6/10, Rn 101; Beschluss des Ersten Senats v. 24.06.2014 – 1 BvR 2926/13 Rn 18.

65 Articles 2(1) & 6(2)(1) *Grundgesetz*.

66 H Zacher, '§ 134/Elternrecht' in J Isensee & P Kirchhof (eds), *Handbuch des Staatsrechts der Bundesrepublik Deutschland: Freiheitsrechte* (2nd edn, Heidelberg, 2001).

67 F Sprecher, Medizinische Forschung mit Kindern und Jugendlichen nach schweizerischem, deutschem, europäischem und internationalem Recht (Heidelberg, Springer-Verlag, 2007), p 17.

The child's best interests in the parent-child-state relationship

Removing boundaries to parental responsibility

These private and public duties towards children revolve largely around the protection and promotion of their best interests. Parental responsibility has marked impacts on the fundamental rights of the child,[68] and so the German Parliament and the *Bundesverfassungsgericht* have sought to remove constraints on who may have parental responsibility when it is in the child's interests for them to have it.[69] The *Bundesverfassungsgericht* has concluded that the purview of Art 6(1) *Grundgesetz* extends to protect families of same-sex couples where only one of the partners is a biological parent of the child.[70] In 1998, the court removed the requirement that the father of a child born out of wedlock could only rely on his parental rights if he lived with the mother and child and, in so doing, exercised parental responsibilities.[71]

Such constraints have been removed in line with the thinking that the child's interests are hindered when those who should be able to exercise parental responsibility are unable to do so. Were the state to deny *person x* parental responsibility over a child, that child would lose the upbringing that *person x* might

68 *BVerfGE* 133, 59, 73 ff, Rn 40 ff; *BVerfG*, Beschluss des Ersten Senats v. 17.12.2013 – 1 BvL 6/10, Rn 101.

69 § 1591 *BGB* has been reinterpreted to confer motherhood upon anyone of an 'indeterminate gender' or to an 'intersex person' provided that person gave birth to the child. See Wissenschaftliche Dienste des Deutschen Bundestags, *Sachstand: Gesetzliche Regelungen der Elternshaft. Ein Überblick über Regelungen der Elternschaft und die Möglichkeit einer Mehrelternschaft in verschiedenen Rechtsordnungen* (WD 7 - 3000 - 146/18, 2018), p 7. See also M Wellenhofer in *Münchener Kommentar zum BGB (MüKo BGB)* (7th edn, CH Beck, 2017) § 1591 Rn 6; H Budzikiewicz in *Jauernig, Bürgerliches Gesetzbuch* (17th edn, CH Beck, 2018) § 1591 Rn 1. In recent years this position has been echoed by the *Bundesgerichtshof*, which has moved away from a constrained gender-based conceptualisation of 'motherhood'. See, eg, *BGH*, Beschluss v. 06.09.2017 — XII ZB 660/14.

70 *BVerfGE* 133, 59, 82 ff, Rn 61 ff.

71 M Jestaedt, 'Artikel 6 II und III' in *Bonner Kommentar zum Grundgesetz* (131st edn, 2007).

bring them. There are nonetheless instances where an individual is not a parent in the legal sense but is entitled to[72] or assigned[73] pseudo-parental authority. However, biological parental rights are generally given priority.[74]

Whereas the state has sought to remove barriers to parental responsibility, it has not attempted so fervently to broaden its own remit for intervention. State intervention with the exercise of parental responsibility is reserved for those instances when the parents' choice is deemed contrary to the child's best interests, when their choice does not sufficiently cater to those interests, or when their decision would be impossible to carry out. In that regard, the state may not intervene without strong justification for doing so, and the *Bundesverfassungsgericht* has consistently upheld this limitation on the state's oversight and voided laws that it believed endangered or posed a threat to the child's right to a guarantee of parental care and upbringing. For instance, a law which enabled a state authority to challenge and subsequently invalidate the father's paternal status was nullified by the *Bundesverfassungsgericht* as it applied retroactively to the day of the child's birth and made no provision for that status to be taken up by anyone else. Children were therefore in danger of being deprived of a father. This interference with the child's rights was considered grave enough for the law responsible to be unconstitutional and therefore invalid.[75]

Interventions to protect fundamental constitutional rights

Some exceptions to the rules limiting state intervention do exist. These exceptions are grounded predominantly in the principle of human dignity and in child's

72 See, eg, step-parents in § 1687b *BGB* and § 9 *LPartG*; and the rights of non-legal fathers to access the child in § 1686a 1(1) *BGB*.

73 See, eg, the assignment of parental-type authority to carers in § 1688 *BGB* (assuming it had not already been transferred to them).

74 *BVerfGE* 79, 15 (60).

75 *BVerfG*, Beschluss des Ersten Senats v. 17.12.2013 – 1 BvL 6/10, Rn 102 f.

fundamental rights to the free development of their personality and to be raised in a family environment.[76] Owing to their vulnerability and status as minors, specific duties are incumbent on the state to guarantee that the child may realise this right.[77] This duty is shared between the parents and the state insofar as the parents are designated as those responsible for guaranteeing the child's rights, with the state 'watching over' the discharge of that duty.[78] Some institutions, such as educational establishments, also carry a level of responsibility for the promotion of the child's interests and are tasked with supporting the parents in their duties. This interplay can give rise to complex relationships, but the position is fundamentally that, 'as a rule, the welfare of the child is closer to the parents' hearts than that of any other person or institution'.[79] In this regard, the protection and promotion of children's interests is left predominantly to the parents, with the state retaining the ability to intervene when the parents fall short of the required standard.

Complexities in these relationships may arise from a strictly-interpreted 'dogmatic basic rights' viewpoint, by way of which children's rights are directed towards the state.[80] The state's obligations to the child require it to facilitate the child's growing up in the custody of their parents as far as possible. To that end, the state provides assistance to parents struggling in their duties to raise their children in situations where the welfare of the child is 'not guaranteed' and help is 'suitable and necessary'.[81] Being that they engage the fundamental rights of the child and of the

76 Articles 2(1) & 6(1) *Grundgesetz*.

77 *BVerfGE* 133, 59 (74), Rn 42.

78 Article 6(2)(1) *Grundgesetz*.

79 *BVerfGE* 59, 360, 376 f = JZ 1982, 325; *BVerfGE* 75, 201, 219 mwN.

80 G Britz, 'Das Grundrecht des Kindes auf staatliche Gewährleistung elterlicher Pflege und Erziehung—jüngere Rechtsprechung des Bundesverfassungsgerichts' (2014) 69 *Juristen Zeitung* 22, 1069.

81 See, eg, § 27 *SGB* VIII (*Hilfe zur Erziehung*).

parents, decisions of this nature are subject to judicial review.[82] In any case, the state's obligations and the parents' responsibilities share the same goal of serving the interests of the child, with the parents exercising their responsibilities independently and with the state being required to intervene to protect those interests if they become imperilled. The corollary of this is that the parents are bound, albeit indirectly, to protect the child's interests.

Britz proposes that, 'not only in the dogma of fundamental rights but in practice, there is something to be gained if one considers parental and children's rights more separately'.[83] Then, 'parallel and opposing interests of the parents and of the child can be more precisely defined and honoured in terms of fundamental rights'.[84] But this is not necessary given that parental rights are 'rights for the benefit of the child, in service of the child'.[85] Closer inspections of Arts 2 and 6 *Grundgesetz* reveal that the law protects the child's interests both *in* and *from* their parents. They are guaranteed the right to be brought up by their parents as part of the family, and in line with the parents' obligations to provide them with good care and upbringing, but they are equally guaranteed protection from their parents should they become unable or unwilling to render sufficiently good care and a decent upbringing. Parental rights therefore have a dual purpose: on the one hand, they guarantee parents the ability to raise their child free from state intervention, save for where they neglect their role in the child's life; on the other hand, they guarantee children the right to an upbringing which will serve their interests whether it be through the parents or the state. They designate the individuals responsible for protecting the

82 Some practical difficulties are encountered in the enforcement of this principle. See, eg, *BVerfG*, Beschluss der 1. Kammer des Ersten Senats v. 17.03.2014 – 1 BvR 2695/13, Rn. 37; *BVerfG*, Beschluss der 1. Kammer des Ersten Senats v. 24.03.2004 – 1 BvR 160/14, Rn 52; *BVerfG*, Beschluss der 1. Kammer des Ersten Senats v. 22.05.2014 – 1 BvR 2882/13, Rn 55.

83 Britz (n 80).

84 ibid.

85 See, eg, *BVerfGE* 59, 360, 376 f.

child's rights and act as a conduit for the child to benefit from them too.[86] In part, this may be due to their formulation as defensive rights against the state which could be formulated alternatively as an obligation incumbent on the state not to intervene unless the parents' conduct warrants intervention. Of particular importance here is the principle of proportionality, in that the state's involvement must be appropriate for the aim pursued.[87] Proportionality is a key principle in German law, being recognised as possessing 'constitutional status'[88] and as a 'transcendent standard for all state action, binding all public authorities'.[89]

86 Article 6 does not confer any rights to the child directly, but the child may be a beneficiary of the rights indirectly under, eg, the parents' rights and duties under Article 6, or—where the child is under guardianship and the guardian does not hold Article 6 rights—the guardian's duties under § 1793 I *BGB*.

87 § 1666a *BGB*.

88 *BVerfG*, Beschluss vom 15.12.1965—1 BvR 513/65.

89 *BVerfG*, Beschluss vom 07.05.1968—1 BvR 133/67.

Translating the parent-child-state relationship into the medical context

The parents' provision of good care is crucial in the clinical setting, where children's rights become hotly contested. Here, the parents' duties to their child individually coincide with the state's obligations towards its citizens and with healthcare professionals' duties towards their patients. Throughout 2019 and 2020, approximately 3,200 children aged 0-5 died, often after a period of palliative care.[90] Of these, around 2,670 died before their first birthday.[91] Until recently, paediatric palliative care in Germany was, 'especially in comparison with Europe, in the early stages'.[92] The first hospital for children in Germany opened in only 1998,[93] though developments and investment since then have brought Germany's capacity to provide paediatric palliative care further in line with other European nations. As will be explored in CHAPTER III concerning England and Wales, German hospitals have faced their own difficulties regarding palliative care provision, particularly for children. In 2012, the Berlin Charité hospital received widespread criticism in the news when it was disclosed that errors in personnel management and a lack of free beds to accommodate a child who was seriously ill with cancer meant that the child could not be admitted. The child died shortly thereafter.[94]

90 Statistisches Bundesamt (Destatis), 'Deaths: Germany, years, sex, age years' (2021), available at <https://www-genesis.destatis.de/genesis/online?sequenz=tabelleErgebnis&selectionname=12613-0003&zeitscheiben=5&language=en#abreadcrumb>, last accessed 16 November 2021.

91 ibid.

92 B Zernikow, *Palliativversorgung von Kindern, Jugendlichen und jungen Erwachsenen* (2nd edn, Berlin, Springer-Verlag, 2013), p 4.

93 M Kuhlen, 'Entscheidungen am Lebensende in der Kinderpalliativmedizin. Ein Erfahrungsbericht aus der klinischen Praxis' (2009) 34 *Historische Sozialforschung* 4, 130.

94 S Dassler & T Loy, 'Drama um krebskrankes Kind an der Charité' *Der Tagesspiegel* (Berlin, 20.11.2012), available at <www.tagesspiegel.de/berlin/eltern-lehnen-beinamputation-ab-drama-um-krebskrankes-kind-an-der-charite/7413334.html>, last accessed 5 February 2021.

Providing the highest possible quality of life for the child whilst continually supporting the child's family has been identified as one of the primary goals of palliative care alongside the mandatory considerations of human dignity and individual rights under the *Grundgesetz*.[95] For this reason, the German Medical Association's explanation of the role of healthcare professionals in end-of-life care is worded in such a way so as to ensure that their duties are discharged in a patient-centric fashion. All the healthcare professionals' obligations towards patients require 'regard to the patient's right to self-determination'.[96] When it comes to very young children, who are not necessarily able to exercise this right, this obligation may extend to further measures which pre-empt potential threats to the right. This was to be observed in the *LG* Köln case, which will be examined later in the chapter. The German Medical Association's word choice also makes clear that care is individual-based, and that healthcare professionals are not duty-bound to continue life at all costs, but instead only 'to preserve life, to protect and restore health, to alleviate suffering, and to assist the dying until they die'.[97] Such an approach is grounded in reasoning similar to that of the *Ethikrat*[98] that death is an individualised process which necessitates respect for patient dignity.

Assistance of this kind is not limited merely to caring for the child patient. Life-threatening illnesses are 'one of the most feared threats to family life',[99] and can often shape the future of a family long after the illness has passed. Consequently, this assistance often involves multi-faceted support for the families, with

95 Kuhlen (n 93).

96 Bundesärztekammer, 'Präambel der Grundsätze der Bundesärztekammer zur ärztlichen Sterbebegleitung' (2004).

97 ibid.

98 Deutscher Ethikrat (n 6).

99 In his capacity as *Bundesminister für Gesundheit* (Federal Minister for Health): H Seehofer, 'Modellprojekt "Schizophreniebehandlung in der Familie"' (Baden-Baden, Modellverbund Psychiatrie, 1993).

considerations made of the impacts of the child's condition and treatment on their family members. German paediatric departments provide bereavement support services to the siblings of child patients, such as access to support groups and counselling,[100] in line with their duties to protect the rights and interests of children and to avoid the negative repercussions which may arise from having to deal unsupported with a sibling's death. Zernikow suggests that, in addition to this provision, siblings should be present in the final stages of the child's life, for it is 'better for the healthy siblings to be with the dying child than to be sent away'.[101] He acknowledges, however, that it is not for healthcare professionals to impose this view upon parents,[102] who should be the arbiters of their own children's interests in these situations given that the parents are best placed to act in their children's emotional interests.

Understandably, the main consideration is of the parents, for whom the circumstances may be the most emotionally taxing and upon whom treatment decisions fall as the 'natural administrators' of the child's best interests.[103] For parents faced with these tough decisions, 'serious illness and death are almost always characterised by recurring phases of hope for a cure and acceptance of an early death'.[104] However, these emotions are often not felt 'in parallel',[105] and changes

100 In 2005, this support was provided to approximately 33% of siblings and to approximately 74% of parents. See S Friedrichsdorf et al, 'Status Quo of Palliative Care in Pediatric Oncology—A Nationwide Survey in Germany' (2004) 29 *Journal of Pain and Symptom Management* 2, 156.

101 Zernikow (n 92).

102 ibid.

103 See, eg, *BVerfGE* 34, 165 (184); *BVerfGE* 60, 79 (94); cf the English law approach of parents being the 'final arbiters' as articulated in B van Leeuwen, 'Free movement of life? The interaction between the best interests test and the right to freely receive services in Tafida Raqeeb' (2020) *Public Law* 3, 498.

104 M Führer, 'Die Rolle des Arztes' in M Führer, A Duroux, & GD Borasio (eds), *„Können Sie denn gar nichts mehr für mein Kind tun?" Therapiezieländerung und Palliativmedizin in der Pädiatrie* (Stuttgart, Kohlhammer, 2006), p 18.

105 ibid.

in the parents' emotions during this process of grieving may be reflected in the decisions they take, or in their engagement and relationships with the healthcare professionals treating their child. It is for that reason that a deterioration in the trust between the healthcare professionals and the parents should be avoided at all costs.

Children's rights, dignity, and endangering best interests

In line with the *elterliche Sorge* and *dienende Rechte* conceptualisations, decisions taken by parents, be they in the clinical setting or in daily-life scenarios, should serve the child's best interests. Protection of the child's best interests and dignity is guaranteed by the state through the demarcation and enforcement of limits on the parents' decision-making authority.[106] The best interests of the child are regarded in practice as being a priority consideration in line with the UNCRC,[107] with the government having recently proposed an amendment to Article 6 *Grundgesetz* to include reference to the child's best interests at the constitutional level.[108] At the core of the child's best interests are the fundamental rights set out in the *Grundgesetz* and in the ECHR and UNCRC, with these interests assessed by reference to the child's position vis-à-vis the state and their parents.[109] When the child's best interests are endangered and there is a foreseeable and reasonably certain danger to the 'physical, mental, or emotional well-being of the child', the state is permitted to intervene.[110]

106 H Schmid & T Meysen, 'Was ist unter Kindeswohlgefährdung zu verstehen?' in H Kindler & S Lillig, et al (eds), *Handbuch Kindeswohlgefährdung nach § 1666 BGB und Allgemeiner Sozialer Dienst (ASD)* (Munich, Deutsches Jugendinstitut eV, 2006).

107 See, eg, See *VG* Berlin, Urteil v. 11.12.1996, 36 X 643.95.

108 This will be explored in Chapter IV.

109 Schmid & Meysen (n 106).

110 § 1666 I *BGB*; *BGH*, Beschluss v. 14.07.1956 - IV ZB 32/56.

The threshold for state intervention must therefore strike a balance between the child's best interests and the parents' Article 6 rights under the *Grundgesetz*. It also requires that any measures taken by the state be 'proportional',[111] in respect of the constitutional positioning of parental rights. This appears to share some similarities with Gillam's proposed zone of parental discretion (ZPD).[112] But greater deference to the parents' choices should not be mistaken for absolute deference. As has been discussed, the rights of the parents are 'serving' rights[113] which exist for the purpose of protecting and promoting the child's welfare. In that regard, the parents' freedom of choice under the German threshold may not be much different from the freedom afforded under the current English system. Given that the threshold is be set against inviolable constitutional rights, it is likely that any decision which even marginally infringes the child's rights or threatens the child's welfare may be susceptible to intervention by the state.

This can extend also to rights, such as self-determination,[114] upon which very young children themselves are not able to act through the principle of proxy consent. Here, 'the law assigns the exercise of the right to self-determination of the child to the persons having the care and custody of the child'.[115] Consequently, the parents are primarily charged with promoting the well-being of the child, and the state acts as a guardian rather than an active decision-maker,[116] under a negative standard[117] which gives the parents some 'elbow-room' provided they do not contravene the

111 § 1666, § 1666a *BGB*.

112 See, eg, Führer (n 104), p 18; L 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* 8, 3.

113 Nave-Herz (n 60).

114 Article 2 *Grundgesetz*.

115 L Roxin, Strafrecht Allgemeiner Teil. Grundlagen: Der Aufbau der Verbrechenslehre, vol. 1 (5th edn, CH Beck, 2006), §13.

116 Article 6(2) *Grundgesetz*.

117 Jestaedt (n 71).

child's rights and general welfare.[118] The parents are recognised absolutely as the primary and central participants in the decision-making process, and no information relevant to that process may be withheld from them, even where that information may not be well-received.[119] In recognition of the parents' role in the process, all possible steps must be taken to reach an agreement between the parents and healthcare professionals before the matter should be referred to court.[120] Such a duty requires the healthcare professionals to consider the potential future requirements of structured communication, therapeutic interventions, and ethical advice and guidance.[121]

Examples of circumstances which may reach the threshold for state intervention are set out by the legislature, though the issue is whether the threshold is reached and not what specific action or omission is responsible for meeting it.[122] Assessments against this threshold are case-specific and consider the age and developmental stage of the child, but incorporate 'physical, mental, [and] emotional' components.[123] Veit notes, however, that isolating individual components within this test is impracticable, for it is entirely possible that physical damage causes mental and emotional effects, with the inverse also being true.[124] Best interests assessments further incorporate social standards and consensuses on the basic needs of children, but—in line with the ZPD—disadvantages which result from 'sub-optimal' parental

118 B Fateh-Moghadam, 'Criminalizing male circumcision? Case Note: Landgericht Cologne, Judgment of 7 May 2012 – No. 151 Ns 169/11' (2012) 13 *German Law Journal* 9, 1131.

119 cf the English-law position in *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

120 DGMR, 'Empfehlungen zur Therapieverweigerung bei Kindern und Jugendlichen' (Medizinrechtlichen Aspekten der Therapieverweigerung bei Kindern und Jugendlichen, Einbeck, 1995).

121 Zernikow (n 92), p 8.

122 M Coester in Staudinger Kommentar zum Bürgerlichen Gesetzbuch, Buch 4, Familienrecht §§ 1638-1683 BGB (13th edn, 2004).

123 Schmid & Meysen (n 106).

124 B Veit in G Bamberger & H Roth (eds), *Kommentar zum Bürgerlichen Gesetzbuch* (3rd edn, Munich, 2003).

decisions do not immediately infringe the child's best interests simply because they are sub-optimal.

Again, this is reflective of the defensive nature of the rights in Article 6 *Grundgesetz*, in that the state's obligation to intervene is only invoked when the care provided by those holding parental responsibility fails to reach a minimum standard, not when it falls short of the maximum or optimum. That is to say that there is no responsibility incumbent upon the state to ensure optimal care and upbringing for all children.[125] Whilst an optimal standard of care for all children is desirable, the necessary interference with parents' rights and responsibilities to raise their children in their own manner is incompatible with both Article 6 *Grundgesetz* and, potentially, Article 8 ECHR. The procedural undertakings which would be necessary to prescribe and to enforce an optimum level of care would also render it impractical. In the absence of a legislative definition or requirement of 'optimal' care, the constitutional protection of human dignity installs an indeterminate baseline threshold below which the standard of care cannot fall. In line with the imprecise definition of human dignity, the threshold is responsive to the requirements of the law and of society: it is 'based on our present understanding of it and makes no claim to timeless validity'.[126] In that respect, the threshold—and subsequent expectations of parents—is able to adapt to new challenges which can impact upon the child's welfare and interests. The emphasis remains upon the parents to protect the child's welfare, and the state takes a background guardian role, intervening only when necessary.

125 *BVerfGE* 60, 79 (94).
126 *BVerfGE* 45, 187 (229).

Interventions by the state are possible where there is an endangerment of the child's welfare which the parents are unable or unwilling to avert. [127] Inability and unwillingness to avert dangers are referred to generally under the umbrella of an abuse of parental responsibility. Notably, refusing medical care for the child on religious grounds may amount to an abuse of parental responsibility[128] because the nature of parental rights as *dienende Rechte* requires that the child's best interests and individual rights take priority over the parents' personal (including religious) convictions. This approach is particularly pertinent for young children, where a brief 'loss' or abdication of parental responsibility can result in serious consequences. [129] In this sense, the minimum level of care required by the constitutional principle of human dignity acts as a 'constraint', as advocated by Beyleveld and Brownsword,[130] on what the child's welfare demands. If decision-making authority, be it the parents' or the state's, is to be exercised in the child's interests, then this baseline threshold adapts to ensure that the child's best interests are at least minimally served by the decisions taken.

There has been some support for the theory that the parents' duty to serve their child's best interests may oblige them to 'give up the hopeless fight with the illness'[131] when their child's condition is severe and has little to no chance of improvement. Indeed, this line of thinking has been explored in England and Wales, where parents (such as Charlie Gard's) are oftentimes driven solely by the hope of a sudden improvement in their child's condition which commits them to making decisions to

127 § 1666 I *BGB*.

128 Veit (n 124).

129 J Münder, B Mutke, & R Schone (eds), *Kindeswohl zwischen Jugendhilfe und Justiz* (1st edn, Juventa-Verlagt, 2000).

130 D Beyleveld & R Brownsword, *Human Dignity in Bioethics and Biolaw* (OUP, 2001).

131 A Freud, Kranke Kinder—ein psychoanalytischer Beitrag zu ihrem Verständnis (Frankfurt, S Fischer Verlage, 1972).

pursue treatment that would otherwise not work.[132] In some cases, misplaced hope based on incorrect information may give the state grounds to intervene on the basis that acting on such falsehoods would cause further suffering for the child and infringe upon their rights to receive good care from their parents. It is possible that this be seen as an abuse of parental responsibility because of an unwillingness to avert a danger, though a delicate balance must be struck between unwillingness which results from an active refusal to act and unwillingness which results from a misinformed but honest, *bona fide* choice to pursue an alternative course of action. Of course, the child's rights and interests must remain the central focus regardless of how well-intentioned the parents may be. The pursuit of satisfying the child's needs is, after all, a goal-oriented process, not a virtue-seeking one.

Healthcare professionals' obligations to the child and the parents' religious views

Since a series of reforms in 1997, centralising the child's best interests in this way has caused some, such as Schwab, to consider the law to be an affront to the parents' rights to raise their child and a 'return to the authoritarian upbringing sovereignty of earlier times'.[133] Concerns of this kind may result from the child's right to a violence-free upbringing,[134] which has been acknowledged as being capable of preventing the parents from consenting to certain medical interventions on their children, such as sterilisation.[135]

132 See, eg, D Tomlinson et al, 'Factors affecting treatment choices in paediatric palliative care: Comparing parents and health professionals (2011) 47 *European Journal of Cancer* 2182.

133 Schwab (n 52), p 305. See also § 1626 *BGB*, para 2.

134 § 1631 Abs. 2 BGB i. d. F. Gesetz zur Ächtung der Gewalt in der Erziehung und zur Änderung des Kindesunterhaltsrechts v. 2. 11. 2000 (BGBl. I S. 1479).

135 § 1631 *BGB*, para 2.

Such a right can also have the effect of precluding the parents from refusing to consent to treatment on religious grounds.[136] When the parents refuse to consent to treatment for their child for religious reasons, or when the parents disagree with one another, an application is made to the family court.[137] The family court then designates an individual guardian who represents the best interests of the child,[138] much like the Official Solicitor in England and Wales.[139] Before the courts seek to pronounce their own judgment, they favour the pursuit of an amicable, consensual settlement of the disagreement between the parents.[140] However, the parents' right to raise their child in line with their religious views—and the consent they give on those grounds—does not override the best interests of the child.[141]

The effect of this is a recalibration of the focus. The German approach continues in its principled approach of assessing the child's best interests in line with the principle of dignity. This is particularly so in cases where the child's body is 'permanently and irreparably changed',[142] such as by circumcision on religious grounds, but this position should be viewed as a pre-emptive defence of the child's self-determination rights and of dignity rather than an assault on the parents' decision-making rights.[143] Indeed, the language of 'permanently and irreparably

136 Veit (n 124). This is also reflected in the Declaration of Ottawa on the Right of the Child for Health Care (50th World Medical Assembly, Ottawa, 1998), para 11.

137 W Eisenmenger & RJ Jox, 'Pädiatrische Palliativmedizin: Die juristische Sicht' in M Führer, A Duroux, & GD Borasio (eds), *„Können Sie denn gar nichts mehr für mein Kind tun?" Therapiezieländerung und Palliativmedizin in der Pädiatrie* (Stuttgart, Kohlhammer, 2006), p 51.

138 §§ 1896-1908i *BGB*.

139 The Official Solicitor 'acts on the patient's behalf' and represents their best interests in Court of Protection hearings, *not* the patient themselves. See P Bartlett, 'Litigation Friend or Foe? Representation of 'P' before the Court of Protection' (2016) 24 *Med LR* 3, 333.

140 M Karle & S Gathmann, 'Hearing the voice of the child: The state of the art of child hearings in Germany. Results of a nationwide representative study in German courts' (2016) 54 *Family Court Review* 2, 167.

141 *LG* Köln, Urteil v. 07.05.2012 – 151 Ns 169/11.

142 ibid, [15].

143 A similar perspective may assist with understanding the 'affronts' to parental involvement in decision-making that were discussed in the *Gard* litigation.

changed' carries with it some degree of aversion, perhaps a consideration of Germany's history, but certainly a consideration of the inviolability of the individual.[144] Importantly, the parents' rights to raise their child do not permit any actions which may override the right of the child to self-determination at a time in the future when they are able to exercise them. The *Landgericht* declared that parental rights are not

> 'unreasonably affected if [the parents] are required to wait and see whether the [child] later decides […] as a visible sign of belonging to Islam'.[145]

The constitutional protections of children's rights therefore have preventative as well as curative measures. Inasmuch as they remedy situations in which the child's rights have been infringed upon, they seek where possible to mitigate the possibility of any future situations arising where the child (who may then even be an adult) finds that the purview of their rights has been curtailed by a previous parental decision. This is equally reflected in the *SorgeRG*, by way of which parents are to 'strive for mutual agreement' with the child regarding the exercise of parental responsibility as far as the child's capacity allows this.[146] In the cases of very young children, this is not possible, though the law appropriately recognises that the future interests of the child should be given appropriate weight in the decision-making process when the child will later gain the ability to make that decision themselves. There appears, therefore, to be a balancing act at play which considers on one hand the parents' rights and responsibilities to raise their child and to make decisions for their child; and on the other hand, the proposed course of action, its potential impacts on the child's life, and whether it would be better to allow the child to make

144 Article 1(1) *Grundgesetz*.
145 *LG* Köln, Urteil v. 07.05.2012 – 151 Ns 169/11.
146 § 1626 Abs. 2 *BGB* i. d. F. *SorgeRG*.

this decision themselves when they are able to. In terms of best interests, the child's future self-determination rights seem to weigh heavily in the assessment.

When it comes to assessing the best interests of children in light of the parents' religious views, two contrasting approaches can be found in *Raqeeb* and the German religious circumcision case. Whilst the two cases are not immediately comparable on their facts, it is possible to draw comparisons from how the courts weighed the religious wishes of the parents in assessing the child's best interests. In *Raqeeb*, the court was satisfied that Tafida shared her parents' religious views and had made a conscious decision for herself to follow Islam despite being only four. Conversely, the *Landgericht* in the German case—where the child was also four—held that his consent was 'not available and was not considered due to a lack of sufficient maturity'.[147] It then assessed that, whilst the parents' consent was available and given, it was nonetheless unable to justify the 'factual assault' on the child.[148] As such, whilst the parents were *able* to consent to it, the treatment was impermissible because the child's future rights to self-determination—ie the ability to make the decision themselves at a later date—were given greater weight than the parents' wishes. In the absence of proper contemporaneous consent from the child, the court found that it would have been inappropriate merely to assume the child's assent to the procedure. Instead, it held that the better approach would be to wait until the child reached the requisite level of maturity to make this decision themselves. Such an assessment of proportionality reflects the hierarchical delineation of rights and the nature of parental rights as rights of service which must be exercised to the benefit of the child's interests.

147 *LG* Köln, Urteil v. 07.05.2012 – 151 Ns 169/11, [14].
148 ibid.

Conflicts such as these are not of the magnitude seen in England and Wales. In England and Wales, there is often a direct disagreement between the parents' wishes and the healthcare professionals' conceptualisations of the child's best interests, with the result that any subsequent litigation must be resolved in favour of one subjective argument or the other. In Germany, the resolving of disagreements is assisted by the existence of the rights under the *Grundgesetz*, which are in practice 'inviolable', being interfered with only 'pursuant to law'.[149] The high threshold requirement for interventions which may curtail the child's future ability to exercise self-determination, particularly where the parents' religious or ideological inclinations run contrary to or risk disproportionately interfering with the child's best interests, has given rise to some discussion as to whether the parents should have medical decision-making authority, particularly at the end-of-life.

Regulating the private sphere: parents as arbiters of best interests

The central question here is whether the child's best interests are best served by the parents being the decision-makers. Given the constitutional protection of the parents' roles in the process,[150] questioning the appropriateness of parental decisions regarding their child's medical treatment may be seen by some as an unjustifiable assault on parents and the wider family unit.[151] Yet in 2007, the *Bundestag* reiterated that the parents should be the principal decision-makers as regards medical treatment for their children, and that only in cases of blatant breaches or neglect of this duty may the parents be deprived of this decision-

149 Articles 1 & 2 *Grundgesetz*.
150 Article 6 *Grundgesetz*.
151 See, eg, Veit (n 124).

making responsibility.[152] In light of this, the question is not one of *who* is to make the decision. Instead, the concern is

> 'on the basis of what principles or values the decision is made, for the fact is that such decisions are already being made, and inevitably must be made, in modern hospitals'.[153]

The key principles and values which guide parents' decision are to be found in the *Grundgesetz*: namely the principle of human dignity, the child's future ability to exercise their right to self-determination, and the rights of the parents. How parents follow these principles, however, is left to their own discretion. Importantly, the weighting of these principles enables the parents to pursue their own interests without being forever obliged to disregard these interests in favour of what is *optimal* for their child.[154] Largely this is because the parents' right to raise their child in line with their world-views and convictions—the 'self-serving' element—and their duty to serve the child's best interests and promote the child's welfare—the 'child-serving' element—can be understood and determined together.[155] Principles upon which the decision should be made, such as dignity, reside in the confluence of these two elements: when the 'self-serving' and 'child-serving' elements conflict, dignity is engaged and the value of the child as a person pulls the decision in favour of the child's welfare, at the (potential) expense of the parents' wishes. This may result in

152 Deutscher Bundestag, Entwurf eines Gesetzes zur Erleichterung familiengerichtlicher Maßnahmen bei Gefährdung des Kindeswohls (Drucksache 550/07, 10.08.07).

153 H Kuhse, 'The Case for Active Voluntary Euthanasia' (1986) 14 *Law, Medicine and Health Care* 3-4, 145.

154 F Wapler, 'Das Kindeswohl: individuelle Rechtsverwirklichung im sozialen Kontext. Rechtliche und rechtsethische Betrachtungen zu einem schwierigen Verhältnis' in F Sutterlüty & S Flick (eds), *Der Streit ums Kindeswohl* (1st edn, BELTZ, 2017), p 31.

155 C Wiesemann, 'Von der Verantwortung, ein Kind zu bekommen. Eine Ethik der Elternschaft' (2006) 18 *Ethik Med* 213.

situations where respect for human dignity requires a child's treatment to be withdrawn against the wishes of the parents.

When the parents' personal interests collide with their duties towards their child, it is possible that the child's best interests may not be given the weight that they require. Some doubt has therefore been cast on whether the child's best interests are adequately served if the parents make the decision.[156] Two prevailing arguments here are predicated on assumptions concerning the parents' susceptibility to emotion and their lack of expert knowledge of the situation. The first is that parents are unable to make 'good' decisions for their child because they do not have a sufficient understanding of the relevant medical science. The second is that parents should not be expected to make these decisions and should be shielded from the obligation to make them, because of the large emotional burden which may overwhelm them and render them unable to adequately provide for their child's welfare.

Alternative decision-makers have been proposed as better arbiters of the child's best interests and as better promoters of the child's welfare. Often the proposed decision-makers are the healthcare professionals themselves, third-party arbitrators (eg, courts), or clinical ethics committees.[157] What each of these proposed decision-makers have in common is that their decisions would likely result in a medicalisation of the best interests assessment. Such a reductive exercise may in fact be a detriment to the child's interests and an infringement upon the right to be raised within the family unit.[158] Permitting one side of a disagreement to be a judge

156 Zernikow (n 92), p 62.

157 A Dorries, 'Mixed feelings: physician's concerns about clinical ethics committees in Germany' (2003) 15 *HC Forum* 3, 245; LM Kopelman, 'The best-interests standard as threshold, ideal, and standard of reasonableness' (1997) 22 *J Med Philos* 3, 271.

158 Article 6 *Grundgesetz*.

in their own cause while removing the other side's right of reply is neither fair nor sustainable.[159] It is better for the purposes of promoting the child's welfare to have a benevolent but misguided alternative proposed by the parents than no alternative at all, for this would necessitate consideration of the child as a valuable individual rather than as the object of medical concern.

Expert knowledge and 'good decisions' in the child's interests

The suggestion that the parents' lack of expert knowledge is a hindrance to the welfare of the child oversimplifies the complexities of the decision-making process, and so does the assertion that the parents are unable to make 'good decisions' because of this. Parental treatment decisions should not be taken in isolation: rather, they should be facilitated by the healthcare professionals who provide the parents with the requisite knowledge to make the decision. A 'good decision' should not be defined by its weighting in medical science: rather, good decisions should be reached in accordance with the principle of human dignity, which should act as the basis of the decision to be made. If human dignity necessitates respect for the individual as a person, then it would not be sufficient to base the decision purely on medical science or purely on parental knowledge of the child. Neither the healthcare professionals nor the doctors are conferred the exclusive right to decide.[160] In some circumstances, compliance with the principle of human dignity may necessitate the decision to withdraw treatment from a seriously ill child.

159 cf *McGonnell v United Kingdom* (2000) 28488/95 ECHR 62.

160 PR Helft, M Siegler, & J Lantos, 'The rise and fall of the futility movement' (2000) 343 *New England J Med* 4, 293.

Emotional burdens impacting upon child welfare

The respect for the individual child patient necessitated by the principle of human dignity further requires that the parents be able to participate in the decision-making process. It is the parents who know their child best as a person and so their input is essential to ensure that the principle is properly adhered to. Excluding them from this process as a paternalistic means of protecting them from taxing emotional burdens runs contrary to empirical research conducted both in Germany and in England and Wales. Parents generally express strong desires to be involved in the decision-making process, even where they would become susceptible to strong emotional burdens.[161] Parents who are included in the process feel able to do all that they can to promote the welfare of the child, whilst those who are excluded from the decision-making process are less likely to trust the healthcare professionals and the relationship between them is at greater peril of breaking down.

Feeling emotional is also not limited to the parents. It is often all too easy to forget that the healthcare professionals responsible for treating a terminally ill child may also feel strongly about the decision to be taken. Proceeding on the erroneous assumption that only the parents are susceptible to being overwhelmed by emotion would risk alienating them. Dismissing their attempts to participate in the decision-making process as histrionic may result in their being stripped of their responsibilities towards their children at the behest of those who disagree with their choices. Instead, parents should be supported and encouraged to take part in the process as much as possible, not least for the purposes of their own emotional

161 This is generally well-documented in Germany and beyond. See M Führer et al, 'Entscheidungen am Lebensende in der Kinderpalliativmedizin: Fallberichte und ethisch-rechtliche Analysen' (2009) 157 *Monatsschrift Kinderheilkunde* 1, 18; KH Abbott et al, 'Families looking back one year after discussion of withdrawal or withholding of life-sustaining support' (2001) 29 *Crit Care Med* 197.

wellbeing, but to allow them to carry out their duties towards their child. Disagreement over what is best for the child does not immediately mean that one side is wrong or should be excluded from the decision-making process.

Conclusion

Making decisions regarding the medical treatment of children in Germany is a process governed largely by the interaction between fundamental rights found in the *Grundgesetz*. As a result of this, all parties to a dispute over the decision to be taken have comparable obligations to serve the child's best interests, though these obligations inevitably manifest themselves in different proposed solutions. At the core of these fundamental rights is the principle of human dignity, which is of great legal, political, and cultural significance. As such, the *Grundgesetz* mandates that the state respect and protect human dignity. It also provides the basis of the right to individual self-determination. Very young children are not able themselves to exercise self-determination: instead, they rely on their parents to raise them compatibly with these rights and principles such that, when they reach a sufficient level of maturity, they are able to exercise them themselves. It is for that reason that parental rights are constructed as responsibilities which parents are to discharge in service of their child's rights and best interests. It is also for this reason that the state is empowered to intervene generally to protect human dignity, and more specifically when it is determined that a child's rights and interests are not sufficiently being promoted.

These rights function as the bedrock of contemporary German society to entrench the value and rights of the individual against the backdrop of a troublesome national history which trampled over personal autonomy and integrity. The protection of human dignity and the rights under the *Grundgesetz* apply universally to all Germans, including those who have not yet been born.[162] As protectors of their child's rights, parents may raise their child in a way compatible with their own lives

162 The *Bundesverfassungsgericht* has taken this position in relation to abortion. See *BVerfGE* 39, 1; *BVerfGE* 88, 203.

provided that this does not come into contention with or jeopardise the child's own rights.

State intervention of this kind became possible with the liberalisation of societal attitudes towards the parent-child relationship, with the entirely paternal authority of *väterliche Gewalt* evolving into *elterliche Sorge*, a responsibility that is more shared between the parents. The modern parental concern has been reframed as a means of promoting the welfare and constitutional rights of the child rather than being an unquestionable power of one or both parents to determine the child's life as they please. As a result of this, the state and the parents share a common interest in promoting the welfare of the child and guaranteeing its constitutional rights. At times, however, this results in the state intervening where in the times of *väterliche Gewalt* it did not.

The implications of this dualistic pursuit of the same goal include the possibility that the parents' choices may be disregarded on the basis that they are not in the best interests of the child. Whilst this approach is shared with England and Wales, Germany diverges on the matter of religiously grounded medical interventions such as circumcision. Whereas, in England and Wales, it is possible for 'two parties jointly exercising parental responsibility to arrange the ritual circumcision of their male child', [163] in Germany this treatment may be rejected on the premise that it constitutes a permanent change to the child's body which they may later, when they are able themselves to exercise their rights, come to disagree with.[164] As noted by the

163 *Re J (Specific Issue Orders: Child's Religious Upbringing and Circumcision)* [1999] EWCA Civ 3022, [6].

164 This is still nonetheless possible. Parents can consent to the 'medically unnecessary circumcision' of their child who is not 'capable of reasoning and forming a judgment, if this is to be carried out in accordance with the rules of medical practice'. Notably, the procedure cannot be undertaken if, 'even considering its purpose, it jeopardises the best interests of the child' (§ 1631d *BGB*).

courts, consent or assent in this sense may not be implied or assumed because the child is not old enough to have any kind of decisional capacity.

This chapter grappled with the argument that the child's best interests are not best served by the parents being the decision-makers. Their legitimacy as decision-makers was examined in light of the purported fallibility of their judgement, which was regarded as unduly influenced by emotions and improperly informed owing to their general lack of medical experience. Ultimately, the chapter concluded that the child's best interests require parental involvement, argument that the parents should not decide was dismissed, for it framed human emotion as a negative characteristic of only the parents and did not adequately acknowledge the role of healthcare professionals in assisting the parents to make the decision.

Chapter III

Common law without common ground: inconsistency and adversity in the approach in England and Wales

There is a voice inside of you
That whispers all day long,
"I feel this is right for me,
I know that this is wrong".
No teacher, preacher, parent, friend
Or wise man can decide
What's right for you—just listen to
The voice that speaks inside.
Shel Silverstein[1]

Introduction

Since the turn of the century, there has been a number of landmark English law cases where the best interests of seriously ill and very young children have been at the centre of disputes between their parents and their treating healthcare professionals. These cases are tragic; they represent for many parents a nightmare situation where their child is dying and the only chance of saving them is through protracted legal battles over their child's best interests. But it is for this reason that they share a communal tragedy, in that the best interests assessment is poorly understood due to a lack of a principled foundation upon which decisions can be

1 S Silverstein, 'Voice' in *Falling Up* (Harper Collins, 2015), p 38.

based. These principles would otherwise provide guidance on how the patient-centric, case-specific approach is to be taken in a way that respects the individual patient whilst maintaining consistency and coherence in the law. The very young children in these landmark cases were incapable of participating in the assessments of their best interests, and the courts' difficulty in being able to locate interests beyond medical indications exemplified the shortcomings of the test and identified areas where concepts such as human dignity may provide clarification. This chapter, therefore, has two main aims. The first is to evaluate the difficulties that arise from such a lack of principle; the second is to explain why this lack of principle and the law's subsequent inconsistent application is a concern for the concept of children's best interests more generally.

The child's position in law has undergone a series of marked changes over the past few centuries. Accordingly, the parents' position relative to their child has shifted. What began with virtually limitless deference to the father's authority in the 19th century evolved into the contemporary approach which sees far greater involvement by public authority alongside the parents to prioritise the child's interests. This chapter will chart the shifting of the locus of control from the father as an ultimate authority (with the mother having no say) to shared parental authority and then to shared parental responsibility, when a parent will not be so simply deprived of any involvement in their child's life.[2] Such historical context is important because it facilitates an examination and understanding of how parental responsibility is exercised in relation to children's best interests, particularly when the interests of the holder of parental responsibility diverge from the interests of the child. Examining this history, the chapter will discuss how children came to be constructed as individual rights-holders and patients as opposed to chattels of the

2 See, eg, Guardianship Act 1973, s 1(1).

parents. Alongside the parents' obligations vis-à-vis the child, it will further examine how increasing regard for the state's obligation to protect the vulnerable has strengthened the frameworks in place to protect children but given rise to complex disagreements over who holds the ultimate decision-making authority.

These developmental foundations are crucial to conceptualising and understanding the changes ushered in by the Children Act 1989 and how the courts responded to their roles as arbiters in the assessment of children's best interests in every-day medical treatment. The chapter will consider the high-profile cases of treating very young children that have informed the legal positions applied by the courts, the practical attitudes employed daily by healthcare professionals in clinical settings, and the opinions of the general public. It will then discuss the judgment in *Raqeeb*[3] to evaluate the potential perils of conflating children's best interests with the interests of the parents and how this can arise from a genuine albeit arguably misguided desire to do what is right.

In light of this discussion, the chapter will compare the approach taken in *Gard*,[4] which concerned the parents' views of their child's best interests, with that taken in *E*, which is one of the most recent examples of disagreement arising between parents and healthcare professionals as a result of the parents' decision to *refuse* life-sustaining treatment for their child.[5] The analysis of *Gard* will demonstrate that the representation of these matters in the media and their subsequent interpretation by

3 *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin), [2019] EWHC 2530 (Fam).

4 *Yates and Gard v GOSH* [2017] EWCA Civ 410.

5 *Cambridge University Hospitals NHS Foundation Trust v Mother of E & Anor* [2021] EWHC 126 (Fam). Unlike *E*, previous landmark cases, such as *Gard*, have involved a determination of the child's best interests where the parents have wished to continue treatment and the healthcare professionals have wished to discontinue. The courts have made clear that healthcare professionals cannot be required to provide treatment that is not clinically indicated: see *Burke v GMC* [2005] EWCA Civ 1003.

members of the general public lead to the perpetuation of misinformation which has two significant effects. The first is that misconceptions over the law as it relates to decision-making in a child's best interests potentially exacerbate disagreements, resulting in a snowball effect whereby a private dispute between healthcare professionals and parents becomes a public polemic. The second is that these misconceptions of how the best interests assessment is applied can lead, and have led, to proposals such as the introduction of the significant harm test found elsewhere in child law.[6] It will be suggested that these proposals would not solve the problem. Rather, issues over the weighting of the parents' views, be they to refuse treatment which is otherwise indicated or to demand treatment that is not indicated, may be dealt with more consistently with reference to the principle of human dignity.

The efficacy of the current frameworks and of the significant harm test shall be compared practically through applying the test individually to *Gard* and *E*. This will enable a critical assessment of how each respects the patient-centric approach advocated in the literature, particularly as it relates to parental decisions which, in the past, would have usually been taken by healthcare professionals. Analysis by such means will also draw attention to the terminological difficulties of both tests in their reference to 'best' interests and 'significant' harm. The chapter will conclude on this front that the proposals to introduce the significant harm test into the medical context would struggle to uphold the same level of protection that the current best interests test does. Indeed, it may even fall short of this level by diminishing the importance of the child's interests in favour of according greater authority to those of the parents. The chapter will also conclude that the significant harm test may incidentally have the effect of reducing the parents' involvement in

6 Children Act 1989, s 31(2)(a).

the decision-making process when it comes to justifying the decisions in disagreement with which the test was originally promoted, such as those where the parents oppose continued treatment.

Ultimately, Chapter III will conclude that the best interests test in England and Wales is constructed in a way that *prima facie* accords sufficient protection to children and to the rights of the parents, but that its inconsistent application in the courts and misrepresentation in the media necessitates a more refined approach with greater legal certainty. However, this approach is not to be found in transplanting the significant harm test into the medical decision-making context. Efforts should instead be focused on strengthening the current system rather than uprooting it. This will be addressed in Chapter IV, informed by the discussion of the principle-based German approach and the pre-eminence of constitutional rights which took place in Chapter II.

The development of parental responsibilities and children's best interests

In order to understand how the relationship between parental responsibilities and the child's best interests has come to be constructed, an acknowledgement of the historical developments of those two elements is necessary. This section will chart this evolution to the modern day and will demonstrate that, until at least 1989, the child's rights and interests were framed in relation to those of the parents, rather than the child being recognised as an individual with separate interests.

At their origin, parental rights were nothing but an anagram of their reality. They were exclusively paternal, with the father enjoying effectively unfettered control over the child under the law. This extended even to the right to prohibit the mother's access to the child.[7] It was 'clear that the custody of a child, of whatever age, belongs to the father', and that 'in whatever principle that right is founded, it is unquestionably established, and is not disputed'.[8] Indeed, it was only in instances where the father forfeited these rights, such as cruelty which endangered the child's life,[9] that this was ever called into question.

Patriarchal attitudes in society and stereotyping of the mother stifled the development of child protection law for much of the nineteenth century. They continue to stifle the development of other areas of law even today. In Westminster, legislators suggested that, were mothers to be granted parental rights, 'no woman of a delicate mind would submit to call upon a court to interfere and to exercise these

7 This thesis uses the terms 'mother' and 'father' in emphasis of the parental relationship so as to retain the focus of these legal developments on the child.

8 *De Manneville v De Manneville* (1804) 10 Ves 52, 63.

9 'The Law in Relation to Women' (1887) 128 *The Westminster Review* 702.

powers' against the father.[10] The courts refused to enforce contracts where the father voluntarily gave up these rights and then reversed that decision, even when this was done with the acknowledgement that the child would fare better in the care of the mother.[11] The primacy of the father's rights meant that mothers were 'caught up in a net of legal and social constraints'[12] and that the children were seen as no more than chattels of the father. This position was reflected in the law. Children under fourteen would be surrendered unconditionally to the father, and the views of children older than fourteen were by no means determinative.[13]

So pervasive and engrained was the derogation to the father's authority that, even where the father had struck or otherwise abused the child's mother, provided there was no threat to the *child*, the paternal authority over the family unit remained absolute. Victim-blaming was a practice rife and commonly accepted when the perpetrator was a man. Mothers who were subjected to abuse by violent fathers were framed as the causes of that abuse rather than the victims. For the courts, were the mother to remain in the home, it would 'subject [the father] to an influence exciting and tempting him to violence towards her'. Conversely, 'to leave his little child in the house is [...] to introduce a soothing influence to [...] mitigate the bitterness of his lot, and bring out the better part of his nature'.[14] It was therefore incumbent on the mother to move, lest the father be induced into violence. Yet, it was of no concern to the court in this case that the vulnerable four-year-old girl be left with the father, for her presence was regarded as a mitigating factor which would 'cheer his darkness'.[15] The court did not entertain the possibility that any violence towards the mother

10 F Shaw, 42 *Hansard* 1053 (May 9, 1838).
11 *Westmeath v Westmeath* (1821) Jac, 125, 37 Eng Rep 797.
12 D Wright, '*De Manneville v De Manneville*: Rethinking the Birth of Custody Law under Patriarchy' (1999) 17 *Law and History Review* 2, 247.
13 *Ex parte Skinner* (1824) 9 Moore CP 279.
14 ibid.
15 ibid.

might affect the welfare of the child because they were not presented with any evidence of the child being targeted directly, despite being presented with evidence of the father's apparent unsuitability for parenthood.

Progress towards a more equitable system was slow until the end of the nineteenth century. References to a primitive best interests test began to be made, with this including the 'tender years' doctrine. Despite the tender years doctrine providing support for the mother as the best-placed parent to take care of their children in their 'tender years', the courts did not interfere with the father's control and did not formally recognise any maternal rights. Such a laissez-faire approach resulted in the best interests assessment in *Agar Ellis* being highly limited, for

> 'it is not the benefit to the infant as conceived by the court, but it must be the benefit to the infant having regard to the natural law which points out that the father knows far better as a rule what is good for his children [than] a court of justice can'.[16]

Under such a formulation, the best interests assessment was not much more than a reaffirmation of the father's absolute power to decide and of the child's status as nothing more than a dependent. They were still treated as tools and objects of the father's benefit rather than individuals in their own right.[17] Clearly any impetus for change would not come from the courts. Nonetheless, 'a public discourse arose in which competing views of maternal and paternal functions were hotly contested',[18] and societal attitudes shifted towards a position that was more compatible with

16 *Re Agar Ellis* (1883) 24 ChD 317, 50 LT (ns) 161 (Bowen LJ); *Re Fynn* (1848) 2 DeG & Sm 457; *Re Curtis* (1859) 27 LJ (ns) Ch 458.

17 See SSF Regilme & KV Feijoo, 'Right to Human Dignity' in S Romaniuk, P Marton (eds), *The Palgrave Encyclopedia of Global Security Studies* (Palgrave Macmillan, 2021).

18 Wright (n 12).

what may now be recognised as human dignity, even though this was not explicitly recognised at the time. Child protection legislation began to be introduced which acknowledged the child as an individual with their own interests separate from the parents'. This important step forward nonetheless came only after similar legislation had already been passed to protect pets and domestic animals.[19] Increasingly, the issue of children's interests began to permeate the discussion, though the historical challenges of reconciling the once-exclusive paternal rights with the relatively novel concept of maternal rights meant that the early children's best interests assessment was not codified in statute until 1925.[20] The assessment had existed nominally since 1745, but only in the Court of Chancery, and was nonetheless subservient to the supremacy of the father's rights,[21] as with the *Agar Ellis* formulation. Yet, 'socially and legally, what it meant to have custody was changing': the law was 'slowly [beginning] to address [...] nurturance, moral and religious training, and social improvement',[22] rather than simply having control.

The codification of the best interests standard and legislation introduced in the 1880s to prosecute child cruelty represented a significant step away from the view that children were the chattels of their parents. Children were increasingly recognised as individual legal persons with their own interests, with the focus moving from the parents' desires to the child and their best interests which required observation by the parents.[23] The second half of the twentieth century saw some of

19 MDA Freeman, 'Upholding the dignity and best interests of children: international law and the corporal punishment of children' (2010) 73 *Law and Contemporary Problems* 2, 211.

20 Guardianship of Infants Act 1925, s 1.

21 *Smith v Smith* (1745) 3 Atk 204, Lord Hardwicke LC: 'it is not a profitable jurisdiction of the Crown, but for the benefit of the infants themselves'. There were five reasons for interfering with a father's rights: parental unfitness; failure to support the children; insufficient means to support the children; by agreement of the father and a third party; and the father leaving the jurisdiction.

22 Wright (n 12), 257.

23 Guardianship of Infants Act 1886, s 5.

the most notable progress in child protection, motivated politically by an emotional public response to the high-profile deaths of Maria Colwell [24] and Jasmine Beckford[25] before the Children Act 1989 came into force. The 1959 Platt Report on the welfare of children in hospital found that 'the children's physician is conscious [...] of the lasting importance which a stay in hospital may have on a child's life'. It also promoted collaboration and liaison between the doctors and the parents, concluding that 'it should be considered the privilege of the consultant paediatrician or surgeon to report progress personally to parents'.[26]

The earliest instance of the courts answering questions over the provision of healthcare to a child was in the 1976 case of *Re D*,[27] where the court considered the 'caring and devoted', if 'over-zealous'[28] mother's attempts to do her best for her daughter in seeking to subject her to non-therapeutic sterilisation. No questions were to be answered over how the decision-making authority was shared between the parents as D's father was deceased and so the decision fell to her mother alone. *Re D* was a rare example of the child's mother agreeing with the healthcare professionals, even though her reasoning for doing so was unsubstantiated. Thus, the court intervened to pronounce upon the decision of the mother as a result of third-party interest, who applied to the court to intervene on the basis of a 'genuine interest in the child'.[29] Lord Templeman expressed twelve years later that such a 'drastic step' which 'vitally concerns an individual' and brings into issue 'principles

24 PD Scott, 'The Tragedy of Maria Colwell' (1975) 15 *British Journal of J Criminology* 88.

25 An accessible overview of the shortcomings of child protection from 1945-2002 can be found in D Batty, 'Catalogue of cruelty' *The Guardian* (London, 2003) <www.theguardian.com/society/2003/jan/27/childrensservices.childprotection>, last accessed 15 November 2020.

26 H Platt, *Platt Report: The welfare of children in hospital* (London, HMSO, 1959).

27 *Re D (A Minor) (Wardship: Sterilisation)* [1976] Fam 185.

28 ibid, 192.

29 ibid.

of law, ethics, and medical practice' did require the authority of the court to proceed.[30]

It was for the purpose of clarifying those 'principles of law' that saw the first case brought where the court was asked to determine the medical treatment of a child in 1981.[31] A declaration was sought regarding the parents' decision to refuse the life-sustaining treatment of their daughter Alexandra, who had Down's syndrome. An assessment of Alexandra's best interests meant that she was removed from her parents and placed into care for the purposes of the treatment, which the court had authorised on the basis of its protective duties to the child.[32] This case was brought to court at a similar time to the prosecution of Dr Arthur, a paediatrician who had administered a sedative to a baby born with Down's syndrome[33] but maintained that he had a clear conscience as a result of acting responsibly and in respect of the authority of the parents who had rejected the child.[34] The child's interests were entirely overlooked and it seems even the possibility that the child had any individual value whatsoever was similarly disregarded.

The common law evolution of the modern position was subsequently consolidated in the Children Act 1989 and Children Act 2004, the latter of which implemented the UK government's 'sea change'[35] Every Child Matters (ECM) initiative following the death of Victoria Climbié in 2000. At its heart, the Children Act 1989 sought to

30 *Re B (A Minor) (Wardship: Sterilisation)* [1987] 2 WLR 1213. Interestingly, this seems not to be so in the case of vaccination: see *Re H (A Child) (Parental Responsibility: Vaccination)* [2020] EWCA Civ 664.

31 *Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421.

32 See M Freeman, *The Rights and Wrongs of Children* (F Pinter, London, 1983), ch 7.

33 *R v Arthur* (1981) 12 BMLR 1.

34 A Osman, 'Conscience is Clear, Murder Case Doctor Says' *The Times* (3 April 1981).

35 A Gentleman, 'Social policies in the noughties: 10 years of change and controversy' *The Guardian* (2009) <www.theguardian.com/world/2009/dec/16/public-services-policy-review-decade>, last accessed 29 November 2020.

combine public and private law to facilitate the creation of a 'single statutory framework which would reflect a coherent set of legal concepts and principles'.[36] Whilst it was successful in combining the two areas of law under one heading, the law it sought to make coherent still lacks certainty.

36 B Hoggett, *Parents and Children: The Law of Parental Responsibility* (Sweet & Maxwell, 1993), p 9.

The Children Act 1989 and a changing legal landscape

The CA 1989 ushered in a number of legislative changes which clarified the positions of parents in relation to their children, and to one another, in both public and private law spheres. It also introduced procedural changes which sought to streamline the child protection framework and redefine the court's obligation as an undertaking to protect the vulnerable through, for example, the paramountcy principle. Whilst elements of the CA 1989 apply to medical treatment for children,[37] the Act did not seek explicitly to make provisions for medical treatment. It did, however, adopt some of the elements of the *Gillick*[38] judgment from a few years earlier,[39] including the possibility that a child with 'sufficient understanding' may refuse medical examinations and assessments.[40]

What the CA 1989 did make clear was that those who hold parental responsibility enjoy various 'rights' and 'powers' which are expected to be exercised in line with the 'responsibilities' they hold towards the child.[41] Parents are under a legal duty to provide proper medical care for their child,[42] including authorising or refusing to authorise treatment which is otherwise medically indicated.[43] The extent to which this is practicable may vary. It is generally accepted that this responsibility exists only to the extent necessary for the parent to satisfy their obligations to the child,[44] and that in situations such as those where the child is in the care of the local

37 For example, specific issue and prohibitive steps orders under s 8.
38 *Gillick v West Norfolk & Wisbech Health Authority* [1986] AC 112.
39 G Douglas, 'The Retreat from *Gillick*' (1992) 55 *MLR* 4, 569.
40 Children Act 1989, ss 43(8) & 44(7).
41 As defined in Children Act 1989, s 3. Throughout this thesis, 'parents' is used to refer generally to those who have parental responsibility, be they the child's biological parents or not.
42 Children and Young Persons Act 1933, ss 1(1) & 1(2)(a).
43 No doctor can be compelled or required to provide treatment which they do not consider to be clinically indicated or in the patient's best interests: *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [18]; *R (Burke) v GMC* [2005] EWCA Civ 1003, [31], [50-52].
44 *Gillick* (n 38), 184.

authority as a result of care proceedings, the responsibility of the parents may be limited.[45] In emergency situations, the parents may be bypassed altogether.[46] As such, the parents' ability to make decisions exists under the proviso that their decisions are not assessed to be contrary to the child's best interests.[47] The child is 'provided with a protective paternalistic undercoat',[48] which protects the child's interests similarly to how healthcare professionals are provided with the 'flak jacket which protects the doctor from claims by the litigious'.[49] There is some distinction to be drawn here, however, in that the protection afforded to children is offered on the basis that children are vulnerable members of society, whereas the protection offered to healthcare professionals is arguably more policy-based. Institutional cultures to protect the vulnerable from harm and to protect doctors from malicious litigation which would impede their ability to fulfil their duties to the patient produce the inevitable outcome that, of the three parties in the decision-making process, only two are given any kind of meaningful institutional protection.

Seemingly the parents are already at a disadvantage. In this respect, the parents' choices are protected only provided they concur with the choices of the others. Their decision is only determinative of the course of action to be pursued when it is assessed to be in the best interests of the child, or when it concurs with the healthcare professionals' decision. Ostensibly the best interests test offers greater flexibility to the subjective assessments of healthcare professionals than it does to

45 Children Act 1989, s 33(3).

46 Providing medical treatment on the basis of necessity is permissible only for those aged under-sixteen. For those aged over-sixteen, this must be done under the General Legal Authority (GLA) as set out in Mental Capacity Act 2005, s 5; *Gillick* (n 38).

47 M Freeman, 'The Right to Responsible Parents' in J Bridgeman, H Keating, & C Lind (eds), *Responsibility, Law, and the Family* (Ashgate, 2008).

48 R Heywood, 'Parents and Medical Professionals: Conflict, Cooperation, and Best Interests' (2012) 20 *Med LR* 29.

49 *Re W (A Minor) (Medical Treatment: Court's Jurisdiction)* [1993] Fam 64 (Lord Donaldson MR).

the parents. It is possible that the healthcare professionals' decision will be in the best interests of the child, but the inverse is equally possible.

Consequently, the flexibility of the assessment, the inherent subjectivity in determining a very young child's best interests, and the varying levels of protection offered institutionally to healthcare professionals and parents mean that the parents' assessment of their own child's best interests may carry less weight than the healthcare professionals' assessment. Parental decisions regarding their children's best interests face a seemingly uphill struggle. Where the decision is believed to be contrary to the child's best interests, it is challenged, and if found by the courts to contravene those interests, it is overridden. Oftentimes this results from a simple difference in opinion over what is 'best' for the child.

The gravity of the decisions faced by some parents should not be underestimated. From 2004 to 2013, the UK saw a 15% increase in the number of children admitted to paediatric intensive care units,[50] where the majority of deaths result from the withdrawal or limiting of treatment.[51] Medical science has advanced to the point where life-sustaining treatment is more likely to succeed, and fewer children succumb to life-threatening conditions.[52] As a result of advancements in medical science, parents today are faced with making decisions for their children where they are furnished with more information about the misery of the condition than before. Smith sees in this a

50 G Birchley et al, ''Best interests' in paediatric intensive care: an empirical ethics study' (2017) 102 *Arch Dis Child* 930.

51 D Inwald, 'The best interests test at the end of life on PICU: a plea for a family centred approach' (2008) 93 *Arch Dis Child* 248.

52 P Ramnarayan, et al, 'Characteristics of deaths occurring in hospitalised children: changing trends' (2007) 33 *J Med Ethics* 255.

> '*folie à deux*: doctors want to believe that they know more than they do […] and the public like the idea that doctors will cure them or keep them from death'.[53]

Comforting though this relationship may be, it falls apart when healthcare professionals either do not know or do not think that there is any possibility of successful treatment, but the parents hold out hope. The same is true when healthcare professionals believe there is some chance of treatment ameliorating the child's condition but the parents either disagree or do not consider the amelioration to be worth pursuing. These breakdowns must then be resolved by the courts.

Court resolution of disputes over the child's best interests

For the most part, parents and healthcare professionals will agree on treatment for the child. [54] Most frequently, the causes of conflict are breakdowns in communication, disagreements over treatment, and unrealistic expectations of proposed treatment. [55] Disagreements as a result of these are not rare. [56] When conflicts do occur, they are often over questions of the child's best interests or general welfare,[57] but 'there can be a marked shift in focus from consideration of the child's best interests to dealing with the conflict itself'[58] which detracts attention from the child.

53 R Smith, 'The ethics of ignorance' (1992) 18 *J Med Ethics* 117.

54 Heywood (n 48).

55 S Barclay, 'Recognizing and managing conflict between patients, parents and health professionals' (2016) 26 *Paediatrics and Child Health* 7, 314.

56 J Moore & M Kordick, 'Sources of Conflict Between Families and Health Care Professionals' (2006) 23 *J Paediatric Oncology Nursing* 82; G Birchley, 'Deciding together? Best interests and shared decision-making in paediatric intensive care' (2014) 22 *Health Care Analysis* 203.

57 See *Re B (A Minor)* [1981] 1 WLR 1421.

58 Barclay (n 55).

When these disagreements arise, the parents are able to seek other healthcare professionals who agree with their proposed course of treatment and are prepared to carry it out,[59] but the original healthcare professionals may nonetheless seek declarations from the courts that this is against the child's best interests. These disagreements are referred to the courts despite a 'reluctance' to do so arising from 'doubts regarding the efficacy of the legal processes and judgments'.[60] The courts have as recently as 2017, in *Gard*,[61] made clear that their jurisdiction extends to 'the authorisation of treatment, declarations of capacity', and situations where a child is 'deprived of their liberty for the purpose of treatment'[62] through statutory powers under the 1989 Act and the inherent jurisdiction of the High Court.[63] The use of these powers has usually manifested itself in an interventionist approach to override the parents' wishes to refuse treatment in order to save the child's life.[64] Nonetheless, there is now increasing support in the literature for the court's inherent jurisdiction to be curtailed on the grounds that the authority is 'too wide',[65]

59 After *Raqeeb*, Tafida's parents called for the law to be changed such that hospitals be unable to block transferring children to 'reputable' hospitals; 'Tafida Raqeeb: "Law Should Be Revisited", Say Parents' *BBC* (5 October 2019) <www.bbc.co.uk/news/uk-england-london-49944602>, last accessed 19 October 2020.

60 Birchley (n 50).

61 *Yates and Gard v GOSH* [2017] EWCA Civ 410.

62 R George, 'The Legal Basis of the Court's Jurisdiction to Authorise Medical Treatment of Children' in I Goold, J Herring & C Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Oxford, Hart, 2019), p 68.

63 Applications are often brought to appeal to both of these in line with *Re JM (A Child) (Medical Treatment)* [2015] EWHC 2832 (Fam), [2016] 2 FLR 235, but the Supreme Court in *Gard* questioned the requirement of the inherent jurisdiction given that 'applications such as this are provided for by statute' under the CA 1989.

64 *Re S (A Minor) (Medical Treatment)* [1993] 1 FLR 377; *Re O (A Minor) (Medical Treatment)* [1993] 2 FLR 149; *Camden LBC v R (A Minor) (Blood Transfusion)* [1993] 2 FLR 757.

65 I Goold, 'Evaluating 'Best Interests' as a Threshold for Judicial Intervention in Medical Decision-Making on Behalf of Children' in I Goold, J Herring & C Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Oxford, Hart, 2019), p 32. See also C Auckland & I Goold, 'Parental rights, best interests and significant harms: who should have the final say over a child's medical care?' (2019) 78 *Cambridge Law Journal* 2, 287.

'nebulous and ill-defined',[66] and 'simply too broad and amorphous to act as limits in and of [itself]'.[67]

That authority has recently been called upon by the parents of Zainab Abbasi after her father, himself an NHS doctor, was forcibly removed from his six-year-old daughter's bedside at the Great North Children's Hospital in Newcastle following a violent altercation with police.[68] Following the ordeal in which Zainab's parents, Rashid and Aliya, described having received 'appalling treatment', they applied to the High Court to challenge an order preventing the doctors from being named.[69] This attracted commentary from Pavel Stroilov, a consultant at the Christian Legal Centre, who was heavily involved in the response to *Evans* when he was a law student. He accused the doctors treating Zainab of choosing to 'give up on trying to save a patient' and bemoaned the hearing process in the courts as being 'protected from public scrutiny by a minefield of reporting restrictions, and then a death sentence is passed'.[70] Previously, Stroilov had been described by Hayden J as 'fanatical and deluded', pursuing a course of action 'inconsistent with the real interests of [Alfie Evans'] parent's case'.[71] Stroilov's comments formed part of a wider campaign of numerous concerted attempts by groups with interests in the

66 M Hall, 'The Vulnerability Jurisdiction: Equity, Parens Patriae, and the Inherent Jurisdiction of the Court' (2016) 2 *CJCCL* 1, 185.

67 MR Ferrere, 'The Inherent Jurisdiction and its Limits' (2013) 13 *Otago Law Review* 1, 133.

68 T Wyatt, 'Rashid Abbasi: NHS doctor dragged from side of dying six-year-old daughter by police in shocking footage' *The Independent* (3 August 2020) <www.independent.co.uk/news/uk/home-news/rashid-abbasi-bodycam-footage-police-zainab-hospital-nhs-a9651326.html>, last accessed 6 February 2021.

69 'Life-support row parents bid to name Newcastle doctors' *BBC* (5 February 2021) <www.bbc.co.uk/news/uk-england-tyne-55945787>, last accessed 6 February 2021.

70 P Stroilov, 'Lessons to learn from the story of Dr Abbasi's arrest' *Christian Concern* (13 August 2020), <https://christianconcern.com/comment/lessons-learnt-from-the-abbasi-case/>, last accessed 5 February 2021.

71 J Halliday, '"Call from God": American pro-lifer's role in Alfie Evans battle' *The Guardian* (2018) <www.theguardian.com/uk-news/2018/apr/28/call-from-god-american-pro-lifers-role-in-alfie-evans-battle>, last accessed 28 October 2020.

case—often religious groups and frequently American—to delegitimise the courts and their jurisdiction as part of a populist campaign predicated upon misinformation. Deep divisions as a result of religious or faith-based convictions can poison the debate and steal attention from the child's welfare, and they serve only to propagate dangerous and misleading assumptions of how the law functions which are patently incorrect.

Raqeeb and parental involvement in best interests assessments

Religious arguments played a crucial role in *Raqeeb* where the courts resolved the disagreement in favour of the parents' decision which they had made in line with their own religious beliefs. Resolutions such as these require the courts to engage in a delicate and perilous balancing act, with the opinions of the parents who are emotionally invested in securing their view of the best outcome for their child set against the medical views of the healthcare professionals seeking to discharge their duty to the patient consistent with their professional obligations. Generally speaking,[72] the courts decide these disagreements in favour of the healthcare professionals' proposed treatment[73] in line with the principle that the 'whole purpose' of the best interests assessment is for the judge to be the 'final arbiter'[74] in determining what is best for the child. In *Raqeeb*, the healthcare professionals recommended the withdrawal of treatment, seeing it no longer in Tafida's best interests, but her parents did not wish for treatment to be withdrawn under any circumstances in line with the Islamic belief that only God may take life.[75] MacDonald J saw four-year-old Tafida's best interests as being closely aligned with the interests of her parents. It is suggested that this came as a result of Tafida's interests being conflated with those of her parents, augmenting the significance of religion in the case which led to a decision that was not made in Tafida's best interests. Rather, it was made in the general interest. In his judgment, MacDonald J stated that

72 Exceptions include *Re T (Wardship: Medical Treatment)* [1997] 1 WLR 242 (CA).

73 J Bridgeman, 'The Provision of Healthcare to Young and Dependent Children: The Principles, Concepts, and Utility of the Children Act 1989' (2017) 25 *Med LR* 363, 375.

74 B van Leeuwen, 'Free movement of life? The interaction between the best interests test and the right to freely receive services in Tafida Raqeeb' (2020) *Public Law* 3, 498.

75 *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin), [2019] EWHC 2530 (Fam), [12].

> '[i]t is plain on that evidence that Tafida had a growing understanding of the practices of Islam, had developed a concept of the importance of life and an accepting and non-judgmental approach to those with disability'.[76]

It is submitted that MacDonald J's assessment of Tafida's cognitive abilities was only possible as a result of the incorporation of her parents' interests into the assessment. Given Tafida's age at the time—four—the chances of her 'growing understanding' being anything more than merely foundational were low. Her parents were followers of Islam and as such she had been raised in accordance with their religious beliefs. Their ability to do this is not in contention, nor is the reasonableness of the choice. What is disputed here is Tafida's knowledge and appreciation of her own situation. Simply, Tafida did not know, and perhaps could not have known, any different. It is difficult to accept that a four-year-old, having no experience of the possible alternatives, would fully understand the circumstances of a religious upbringing. Despite religion having played a significant role in her life up to this point, Tafida was 'not a Muslim child', but 'a child of Muslim parents', and 'religion is something for her to choose—or reject—when she becomes old enough to do so'.[77] Her understanding of the Islam faith and the role it played in her life was contingent entirely on her exposure to it through her parents. Arguably, religion should have been regarded only as a matter of parental interest and choice, and the prevalence of religion in her life should not have been taken as evidence that she voluntarily belonged to that religion.

The judge's second claim was that Tafida 'had developed a concept of the importance of life'. Similar concerns arise here as did with Tafida's 'growing understanding' of her parents' religion. The court found Tafida's alleged belief in the 'importance of

76 ibid, [166].

77 R Dawkins, *The God Delusion* (Houghton Mifflin, 2006).

life' sufficient to be persuasive in continuing her treatment but subsequently found it 'unsafe to infer from the available evidence an acceptance by Tafida of or wish to live' life in a state of 'minimal awareness with no prospect of substantive recovery'.[78] It is difficult to envisage a basis where 'it is plain on that evidence' that Tafida had engaged in such existential contemplations other than that where her parents' own beliefs and the value they placed on *Tafida's* life—not necessarily even life in general—had influenced the decision.

It is further submitted that the court's conclusion, that Tafida had 'an accepting and non-judgmental approach to those with disability', was given inappropriate weight in the assessment. Concluding as such necessarily requires believing that Tafida understood the nature of disabilities and acknowledged that disabilities give rise to circumstances which some may perceive as grounds to discriminate. As it is unlikely that Tafida understood the lofty concept of the 'importance of life', it is unlikely too that she understood sufficiently the distinction between disability and non-disability. Such a reductive view of disability is not necessarily helpful given also that many disabilities are invisible, but nonetheless the depth of Tafida's understanding—largely due to her age—does not seem to correlate with the significance with which it was attributed by the court.

It is difficult to reconcile these findings with MacDonald J's concluding remarks that

> 'if Tafida was asked she would not reject out of hand a situation in which she continued to live, albeit in a moribund and at best minimally conscious state, without pain and in the loving care of her dedicated family, consistent with

78 *Raqeeb* (n 75), [167].

> her formative appreciation that life is precious, a wish to follow a parent's religious practice and a non-judgmental attitude to disability'.[79]

It is submitted that the court has engaged in an honourable yet misguided attempt to assess Tafida's best interests. What the court held to be Tafida's views and opinions were effectively extrapolated versions of her parents' views and opinions, for Tafida was a four-year-old child living a four-year-old child's life. Life-sustaining treatment was ultimately found to be in her best interests because 'it permits Tafida to remain alive in accordance with the tenets of the religion in which she was being raised',[80] in essence the belief that only God can take life. In light of the above, it is possible that this judgment may be reworded with no loss of meaning as 'it permits Tafida to continue living the life that her parents had chosen for her'. Religious upbringing in this case was far more an interest of the parents than it was of Tafida.

MacDonald J's final statement, where he judged that the answers to the best interests test are found in '"subjective" judgments that derive from the diverse outlooks of different communities in our society', may also give rise to cause for concern. [81] Disagreements over moral matters should not obviate the court's primordial duty to determine the course of action that is in the child's best interests. In *Raqeeb*, the determination of these matters was deferred largely to the parents' interests, with which Tafida's best interests were found to conform. The court 'ruled the decision could be taken by her parents, in the light of their religious beliefs about the sanctity of human life'.[82] The effect of this appears to be that, where a child's

79 ibid, [168].

80 ibid, [173].

81 E Cave & E Nottingham, 'Who knows best (interests)? The case of Charlie Gard' (2018) 26 *Med LR* 3, 189.

82 E Jackson, 'Expert Reaction to Tafida Raqeeb Ruling from High Court' *Science Media Centre* (2019) <www.sciencemediacentre.org/expert-reaction-to-tafida-raqeeb-ruling-from-high-court/>, last accessed 10 November 2020.

parents have strong religious convictions regarding the value of life, it is possible that these views may override other factors of the best interests assessment.

In addition to this, human dignity was also overlooked on the basis that there was 'no evidence before the court to demonstrate that Tafida *herself* would consider her position to be undignified'.[83] This is potentially an over-simplification of the issue: perhaps there was no evidence that Tafida would consider her position to be undignified because, as has been discussed, Tafida was too young to be able to engage in this kind of consideration. This appears also to be a reference to the subjective feeling of indignity rather than to something which runs contrary to the concept of human dignity. Notwithstanding this, the absence of evidence is not evidence of absence. The fact that certain conclusions were able to be drawn on relatively minimal evidence whilst other avenues of consideration were dismissed for a lack of evidence highlights one of the perils of the subjectivity of best interests determinations. It is submitted that greater engagement with the principle of human dignity in *Raqeeb* might have provided a clearer justification for the decision that was made and may have reduced the likelihood that Tafida's interests became fused with her parents'.

Religious freedom in *Raqeeb* and *Fixsler*

Religion also played a significant role in the 2021 case of *Fixsler*, where MacDonald J reached the opposite conclusion when considering the best interests of Alta Fixsler. Alta was a two-year-old girl with Hasidic Jewish parents who, much like Tafida's parents, did not wish for treatment to be withdrawn because the sanctity of life was a fundamental value in their beliefs. He considered that this assessment

83 *Raqeeb* (n 75), [80].

> 'must take into account the particular religious, cultural and ethical context [...] provided by the fact that Alta is an Israeli citizen the fact that the family intended to emigrate with Alta to Israel and the family's Orthodox Jewish beliefs and that the assessment of her best interests must be informed by consideration of the religious and cultural values of the family, and by recognition that religious and ethical frameworks governing these subjective factors differ'.[84]

Religion, therefore, appeared to have an importance in Alta's family life similar to the significance it had in Tafida's family life in 2016. But, contrary to his findings in *Raqeeb*, MacDonald J stated that he was

> 'not able, in circumstances where Alta suffered a brain injury that left her with no ability to learn about the world around her before she was able to understand anything of religion and culture into which she was born, to accept the submission that the assessment of Alta's perspective on this matter should start by assuming, without more, that Alta would share the values of her parents, of her brother, and of her wider family and community'.[85]

It is difficult to reconcile the varying levels of importance attributed to religion in the best interests assessments in the *Raqeeb* and *Fixsler* judgments. MacDonald J's decision that Tafida understood religion and was voluntarily living compatibly with Islam was predicated largely on her parents' involvement and on her having had, at some point, a cognitive understanding of her circumstances. What this did not mean, however, was that she had a sufficient understanding of her circumstances to

84 *Manchester University NHS Foundation Trust v Fixsler & Ors* [2021] EWHC 1426 (Fam), [71].
85 ibid, [95].

be able to choose for herself to follow any particular religion. In the appeal of *Fixsler*, the Court of Appeal found that 'it is difficult if not impossible to attribute any views, including religious beliefs, to a very young child who has never had, nor will have, any cognitive understanding'.[86] Whilst this is the correct approach to take, a fundamental level of cognitive understanding does not necessarily mean that the child will understand the specifics of their individual circumstances, including the context of their religious upbringing. This is especially so when the child has known no different.

It is further submitted that MacDonald J contradicts his own rationale in *Fixsler*. He stated that Alta would have no understanding of the 'world around her' but then, in applying the best interests test to the question of continued treatment, declared that 'it is more likely than not that Alta's point of view would be that continued life sustaining treatment would not be acceptable to her'.[87] Baker LJ's response to this is simply that, '[g]iven her age and lack of understanding, I think it is impossible to reach any conclusion as to what her views would be'.[88] It is difficult to disagree with this assessment. MacDonald J seems to have run astray of his own reasoning, and given the Court of Appeal finding that his conclusion was an impossible one to have made, questions arise over what—if any—values were employed to reach that decision. This apparent inconsistency is concerning and was able to be re-assessed in Alta's parents' subsequent appeal on this ground.[89]

Religious freedom when it comes to making treatment choices for children is a freedom that necessitates both respect and restraint. There are nonetheless examples of the parents' opinions having been unduly influenced by third parties.

86 *Fixsler & Anor v Manchester University NHS Foundation Trust & Anor* [2021] EWCA Civ 1018, [85].
87 *Manchester University NHS Foundation Trust v Fixsler & Ors* (n 84), [96].
88 *Fixsler* (n 86), [93].
89 ibid.

In the media, selective reporting of the facts and superficial engagement with the difficulties faced by healthcare professionals and the courts fuel public support for the parent's views, which has in the past resulted in threats made towards the treating hospital's staff[90] and the judiciary.[91] Partisan media coverage prejudicing the court of public opinion is not new: this phenomenon occurred in cases predating widespread social media use.[92] However, the prominence of contemporary social media facilitated passionate yet often misguided protest in the most recent high-profile cases of *King*,[93] *Gard*,[94] *Evans*,[95] and *Haastrup*.[96] Social media campaigns and interest groups took a view similar to the courts in 1883,[97] that nobody knows a child better than their parents,[98] and their message was echoed in vitriolic form by 'American religious, so-called pro-life, right-wing groups'. [99] Newspapers and support groups extolled Ashya King's parents' decision to abscond with him to the Czech Republic to pursue alternative therapy which, incidentally, transpired to have potentially fewer side effects than conventional therapy, despite that it 'sparked an

90 B Quinn & K Rawlinson, 'Alfie Evans: police issue warning over online abuse of medical staff' *The Guardian* (2018) <www.theguardian.com/uk-news/2018/apr/25/alfie-evans-struggling-after-treatment-withdrawn-court-told>, last accessed 27 October 2020.

91 Hayden J was labelled a murderer and a torturer, with a doctored image of his face featuring a toothbrush-style moustache circulated online: M Scott, 'No, we don't need an Alfie's law' (Barrister Blog, 2018) <https://barristerblogger.com/2018/04/30/no-we-dont-need-an-alfies-law/>, last accessed 21 October 2020.

92 *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] Fam 147; *Re Wyatt (A Child) (Medical Treatment: Parent's Consent)* [2005] EWHC 693 (Fam); *Re OT* [2009] EWCA Civ 409.

93 *Re King (A Child)* [2014] EWHC 2964 (Fam).

94 *Great Ormond Street Hospital v Gard & Others* [2017] EWHC 1909 (Fam).

95 *King* (n 93); F Nelson, 'The agony of Alfie Evans' parents was made worse by bad law' *The Spectator* (2018) <www.spectator.co.uk/article/the-agony-of-alfie-evans-parents-was-made-worse-by-bad-law>, last accessed 29 October 2020.

96 *Kings College Hospital NHS Foundation Trust v Haastrup* [2018] EWHC 127 (Fam).

97 *Re Agar Ellis* (n 16).

98 As acknowledged in *Re Wyatt (A Child) (Medical Treatment: Parent's Consent)* [2004] EWHC 2247, [34].

99 A Gallagher, 'What can we learn from the case of Charlie Gard? Perspectives from an interdisciplinary panel discussion' (2017) 24 *Nursing Ethics* 7.

international manhunt'.[100] *Gard* was 'rocket fuel for the tabloids',[101] pervaded by 'key strategies of populism [...] to misunderstand and misrepresent evidence, science and law, and to malign public institutions',[102] with the case being 'exploited for political and spiritual gain'.[103] Little genuine regard was to be had for the desperately ill child save for that which served a politically or religiously expedient aim, and the wealth of misinformation can lead to a breakdown in trust which may 'escalate into a damaging conflict for all parties'.[104] The rest of this chapter will assess the implications of these relationships of trust on the child's best interests in two cases: *Gard*, where Charlie's parents fought for his continued treatment against the healthcare professionals' advice, and the 2021 case of *E*,[105] where the healthcare professionals proposed continued treatment, but this was refused by the seven-and-a-half-year-old child's mother.

100 G Mezzofiore, 'So Ashya's parents were RIGHT: Proton beam cancer therapy that forced family to go on the run to Spain because they couldn't get it on the NHS is as good as chemotherapy—and has fewer side effects' *Daily Mail Online* (2016) <www.dailymail.co.uk/news/article-3424058/So-Ashya-s-parents-RIGHT-Proton-beam-cancer-therapy-forced-family-run-Spain-couldn-t-NHS-good-chemotherapy-fewer-effects.html>, last accessed 2 November 2020.

101 R Hurley, 'How a fight for Charlie Gard became a fight against the state' (2017) 358 *BMJ* 3675.

102 ibid.

103 J Street-Porter, 'I know how Charlie Gard's parents feel—but their trauma shouldn't be exploited for political gain' *The Independent* (2017) <www.independent.co.uk/voices/charlie-gard-gosh-great-ormond-street-hospital-ruling-pope-donald-trump-a7829351.html>, last accessed 31 October 2020.

104 T Stammers in Gallagher (n 99).

105 *E* (n 5).

Reconciling opposition and significant harms in *Gard* and *E*

Parents opposing the withdrawal of treatment in *Gard*

Confronted with the potential loss of their young child and spurred on by widespread international support, the parents of Charlie Gard—Connie Yates and Chris Gard—fought fervently for what they considered to be in their son's best interests. His rare condition, infantile onset encephalomyopathic mitochondrial DNA depletion syndrome (MDDS), left his parents only the minute, misguided hope of experimental nucleoside supplementation therapy saving their child. It was a cause they championed and fought for passionately. The treatment, which they described as pioneering and life-saving, had never been attempted in an animal with Charlie's condition, let alone a human, and was opposed by the healthcare professionals who believed that keeping him alive was not in his best interests. In court, the judgment in *Wyatt*, that '[t]here is a strong presumption in favour of a course of action that will prolong life, but that presumption is not irrebuttable'[106] was reiterated alongside the judgment in *Re J* that the presumption in favour of life is rebutted—that is, continued life is deemed not in the child's best interests—where it would be 'intolerable to the child' and 'bound to be full of pain and suffering'.[107]

Yet outside the courtroom, many supporters of Charlie's parents and of his 'fight'[108] lamented the hospital holding him captive[109] and the 'death panels'[110] responsible for

106 *Wyatt* (n 98).

107 *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930, [1991] Fam 33 (CA).

108 Much of the language used in the public campaign was militaristic: supporters of Connie and Chris' legal battle were referred to as 'Charlie's army', with Charlie's own ordeal described as a 'fight'.

109 R Mendick, 'Charlie Gard is being held 'captive' by the NHS, complains the family's spokesperson' *The Telegraph* (2017) <www.telegraph.co.uk/news/2017/07/12/charlie-gard-held-captive-nhs-complains-familys-spokesman/>, last accessed 30 November 2020.

110 Hurley (n 101).

authorising the withdrawal of treatment, likening their behaviour to the '"categorisations" of people unworthy of life under the Nazis'.[111] Allegedly, this was the scandalous result of 'increasing arrogance, ultra-paternalism and [...] authoritarianism of the elite of functional experts'.[112] Whilst sensationalist and opportunistic coverage of the case was widespread, few went as far as to publicly liken the healthcare professionals treating young children to the Nazis. However, as easily as these commentaries may be dismissed as manifestly ill-conceived and malicious, the sentiment raises a genuine concern. CHAPTER II has already showed that concerns over a repeat of the horrors of the Nazi regime pervade and often determine the approach to the law in Germany. In this instance, however, the concern appears to be entirely misplaced.

Charlie's parents were spurred on by individuals who supported their views as a result of personal (largely religious) convictions, of misinformation in the media, or of some combination thereof. It is entirely possible that, for a small subset, the fate of Charlie Gard was inconsequential: the case was more a means of projecting their views and an opportunity for political point-scoring than it was about seeing the best done for Charlie. In court proceedings, Charlie's parents sought to rely on Article 8 ECHR to support their claims to the decision-making authority over Charlie's treatment and to argue that the best interests assessment had been improperly conducted. Their view was that the protection of their private life accorded to them under Article 8 should extend to their ability to make decisions regarding Charlie's healthcare up to the point that the decision caused, or risked causing, significant harm. As such, they sought to convince the court that the parents should make decisions free from intervention by the courts unless there was

111 S Krason, 'The Charlie Gard Case: A Coming Together of Current Troublesome Realities' (2018) 23 *Catholic Social Science Review* 367.

112 ibid.

reason to believe that the child would be harmed as a result. This was in line with the threshold of significant harm. However, this was unequivocally rejected,[113] with the position articulated in *An NHS Trust v MB* by Holman J remaining the guiding principle of law. Holman J said that the parents'

> 'wishes, however understandable in human terms, are wholly irrelevant to the consideration of objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship'.[114]

There is consensus that the law was properly applied.[115] Cave and Nottingham highlighted that 'to have decided otherwise would have perpetuated a line of reasoning that would frustrate progress in protecting children's rights'.[116] Certainly the rhetoric used in campaigns for Charlie's treatment represented a threat to children's rights, in that allowing the parents to make the decision under the significant harm arrangement would have risked returning the legal position to one where children are susceptible to negative effects of their parents' decisions with reduced intervention by the state to protect them.

Responding to the *Gard* judgment, Gillon proposed that

113 *GOSH NHS Foundation Trust v Yates and others* [2017] EWCA Civ 410, [105].
114 *An NHS Trust v MB* [2006] EWHC 507 (Fam).
115 Cave & Nottingham (n 81), 500.
116 ibid, 504.

> '[t]he court could and should have avoided depriving the parents of their normal moral and legal right and responsibility to decide on their child's best interests'.[117]

It is submitted that the notion of the parents being 'deprived of their normal moral and legal right' is misleading and predicated on a regrettably commonplace misunderstanding in the literature which supports the introduction of the significant harm test. There is a *crucial* difference between parents being deprived of the opportunity to exercise their rights and an intervention to regulate the exercise of those rights in the child's interests. Charlie's parents were actively involved in the process inside and outside the courtroom and were able to petition courts at various levels, including the ECtHR (albeit unsuccessfully),[118] without impediment. They were able to, and did, exercise their parental rights to their fullest possible extent within the reasonable bounds of the law. Were they to have been conferred rights beyond this, such as the right to make an authoritative decision, this may have had the effect of depriving Charlie of his rights. Stripping him of his 'normative significance within law' would, per Riley, be an affront to human dignity.[119]

Despite consternation that it may have 'sheltered itself'[120] with its previous ruling in *Lambert v France* (that a lack of European consensus on end-of-life care and euthanasia means a wide margin of appreciation is afforded to states party)[121] the

117 R Gillon, 'Why Charlie Gard's parents should have been the decision-makers about their son's best interests' (2018) 44 *J Med Ethics* 462.

118 *Charles Gard & Others v The United Kingdom* (2017) Application 39793/17.

119 S Riley, 'The Function of Dignity' (2013) 5 *Amsterdam Law Forum* 2, 90.

120 G Puppinck, 'Affaire Charlie Gard : la limite du droit des parents au respect de la vie de leur enfant' *European Centre for Law & Justice* (2017) <https://eclj.org/euthanasia/echr/affaire-charlie-gard--la-limite-du-droit-des-parents-au-respect-de-la-vie-de-leur-enfant?lng=fr>, last accessed 5 November 2020.

121 *Lambert & Others v France* (2015) Application 46043/14.

ECtHR was nonetheless clear in its reasoning in *Gard*. It held that the domestic courts

> 'were meticulous and thorough; ensured that all those concerned were represented throughout; heard extensive and high-quality expert evidence; accorded weight to all the arguments raised; and were reviewed at three levels of jurisdiction with clear and extensive reasoning giving relevant and sufficient support for their conclusions at all three levels'.[122]

Concluding that there was no 'element suggesting that those decisions could amount to an arbitrary or disproportionate interference' with Charlie's parents' rights,[123] the ECtHR dismissed the petition, adjudging it 'manifestly ill-founded'.[124] This outcome would not have been changed were the significant harm test to apply, though the possibility would have existed that their application be adjudged 'manifestly ill-founded' alongside their parenting decisions being considered 'significantly harmful' to their child. Reframing the argument as giving the parents *more* rights would fail similarly to address the issue, as the significant harm test would not in practice do this. Instead, it would increase the protection given to their existing rights by raising the threshold that must be reached in order for them to be intervened upon, with the effect of this being a reduction in the protection that is immediately available to the child. Both the Court of Appeal and the Supreme Court found that, were they to apply the significant harm test advocated for by Charlie's parents, continued treatment would pose a risk of significant harm of 'continued

122 ibid, [124].
123 ibid.
124 ibid, [125].

pain, suffering, and distress' to Charlie,[125] and that 'experimental treatment with no prospects of success would offer no benefit and prolong his suffering'.[126]

Parents opposing the continuance of treatment in *E*

In contrast with *Gard*, where the parents opposed the healthcare professionals' decision to withdraw treatment, E's mother opposed the healthcare professionals' decision to continue treatment. Both cases involved a breakdown of the relationship of trust that once existed between the parents and doctors, and *E* concerned also the decision-making process where one of the parents was absent. What follows will nonetheless show that, almost invariably, the courts will defer to the professional experience and knowledge of the healthcare professionals and declare that their decision should be the one to be followed.

At the time of the case, E was seven-and-a-half. Some four years before, she was diagnosed as having a medulloblastoma—a cancer in her brain—of a type which was incurable by surgery alone. She underwent treatment at the Addenbrookes Hospital in Cambridge and her mother was informed that she should undergo further supplementary treatment to prevent the return of a tumour. These supplementary treatments were either radiotherapy or chemotherapy, or a combination of the two. The form of radiotherapy which would have been employed was 'known to cause permanent damage to a young child's immature and developing brain' and so the treatment was not routinely available to children aged under five,[127] despite the treatment allegedly being available to children aged under five in America.

125 *Gard* (n 118), [30] and [36].
126 ibid, [120].
127 *E* (n 5), [3].

In light of the caution against craniospinal radiotherapy for children of E's age, chemotherapy was pursued. The results of this treatment were 'rapidly catastrophic' and were not foreseen by the doctors at Addenbrookes who, from the time of E's deterioration to the hearing in January 2021, could provide no explanation for her devastating reaction to the treatment. She had fallen into a coma and was seriously ill for several months, spending over a month in the intensive care unit and coming close to death on more than one occasion. Nonetheless, she was able to return home and go to school, though because of her reaction to the chemotherapy, the microscopic cancer cells which that treatment would have removed had not been sufficiently treated. Aged five-and-a-half, E was required to undergo further treatment for a tumour which had returned. She was treated at Alder Hey Children's Hospital in Liverpool, the hospital which years before had cared for Alfie Evans and had become embroiled in a legal battle with his parents. After the procedure, the treating healthcare professionals at Alder Hey 'expected that E would now have craniospinal radiotherapy at Addenbrookes to prevent recurrence'.[128]

E was now of a suitable age for craniospinal radiotherapy but did not receive it because her mother decided against it after the advantages and disadvantages were explained to her. E's father did not play any substantive role in the decision-making process as he had been out of her life for many years, though it was incorrectly stated by the court that the father did not have parental responsibility for E, despite it being guaranteed to him by virtue of his being named on E's birth certificate.[129] More accurately, he chose not to participate in the hearing. He acknowledged that having not seen his daughter for a number of years put him in a position where he felt he could not make a decision. He did, however, declare that he wanted E to live 'a happy

128 ibid, [7].
129 Children Act 1989, s 4(1)(a).

life, to go to school and to have fun'.[130] The hospital therefore applied to the High Court for a declaration of the child's best interests.

Of pivotal importance to the disagreement in this case was E's mother's fears and reservations regarding the efficacy of treatment and the capability of the doctors at Addenbrookes to carry out the treatment. Her 'greatest fear' was that the proposed radiotherapy would result in a 'similar adverse and catastrophic reaction'. [131] Effectively, she had lost trust in the treating healthcare professionals and consequently in the treatment's ability to provide her daughter with a good quality of life. Her focus was not on the long-term future ramifications for her daughter. She was much more troubled by the present and the possibility that E once more react severely to the treatment. For her, a 50/50 chance of success was not sufficient to justify subjecting her daughter to treatment which she regarded as perilous. Given that hope and considerations of the child's quality of life are two of the most significant factors influencing decisions of this nature,[132] it is no surprise that the mother was loath to elect to continue pursuing treatment for her daughter. Her focus was on her daughter living the remainder of her life to the full, and she admitted that she opposed further treatment because 'it is very hard for me to see her going through all the suffering and ill effects and maybe still die'.[133]

In his judgment, Holman J avoided making what this thesis has argued to be a mistake by MacDonald J in *Raqeeb*. Whereas in *Raqeeb* the parents' considerations of elements pertaining only to them were conflated with Tafida's best interests, this was not the case in *E*. Holman J explicitly acknowledged that, whilst 'nothing could

130 *E* (n 5), [15].
131 ibid, [29].
132 D Tomlinson et al, 'Factors affecting treatment choices in paediatric palliative care: Comparing parents and health professionals' (2011) 47 *European J Cancer* 2182.
133 *E* (n 5), [34].

be more human and understandable than the mother's position',[134] her 'subjective wishes', including the view that E should not undergo treatment and should 'live the life that is left for her',[135] could not be given full weight in the analysis because they were not aligned with E's best interests. He emphasised that his decision was 'very person-specific',[136] and that there was a 'very real prospect of a cure and a normal life expectancy'[137] enabling him to find that E would 'grasp the prospect of living a full life' which the treatment offered.[138] Nevertheless, the healthcare professionals at Addenbrookes and Holman J himself did make some allowance for the mother's interests alone, entirely separated from the best interests of E, in their consideration of the most appropriate venue for the treatment to be administered. There was thus a balance struck between a conflation of parental views with the child's best interests in *Raqeeb* and the so-called 'deprival of rights' in *Gard*, without recourse to a significant harm test. *E* is an example of the courts making an assessment in the child's best interests before then considering how the decision may be undertaken in a way that accommodates the parents' interests. The consideration of both the child's interests and those of the parents entirely separate from each other should be applauded.

The greater risk of significant harm

The parents' position in treatment decisions would not be helped by transplanting it from the care and supervision frameworks[139] into the medical context. In practice, the significant harm test *lex lata* and Gillam's zone of parental discretion (ZPD)

134 ibid, [45].
135 ibid, [34].
136 ibid.
137 ibid, [46].
138 ibid, [51]. Incidentally, Holman J dismissed the possibility of any curative effects being found in drinking a mixture of bicarbonate of soda and vinegar or in administering coffee enemas.
139 Children Act 1989, s 31(2)(a).

would have made no positive difference in *Gard* or *E*. Charlie's parents' decision may have been permissible despite being sub-optimal but would also have resulted in a 'serious set-back to [Charlie's] interests',[140] which ultimately would have rendered it an unreasonable decision to follow. Undoubtedly, E's mother's decision would have satisfied the threshold for being considered 'significantly harmful' given the potential ramifications of E not being treated compared to the benefits she may have received with the treatment.

Gillam's formulation of the ZPD as including decisions ranging from those 'absolutely optimal for the child's interests, to those which [...] are not so bad as to constitute harm to the child'[141] would raise the threshold for intervention upon parental decisions. As such, parents would have a greater remit to pursue whatever course of treatment they may desire, however advisable or convoluted it may be, provided they do not cause 'harm *overall*'. Such a standard would inevitably give rise to yet more complex moral value judgments. In his response to *Gard*, Gillon argued that 'the court should have acknowledged that assessment of Charlie's best interests depended on how an acute moral dilemma was resolved' and that 'it was not necessary or appropriate for the court to resolve that moral dilemma'.[142]

Such an argument works both ways: one who seeks to legitimise the parents' authority to resolve these moral dilemmas will be met with another who seeks to legitimise the courts' authority to do the same. Faced with this impasse, it becomes apparent that the process is lacking guidance in the form of a foundational principle such as human dignity. Greater engagement with dignity may also assist in

140 J Feinberg, *The Moral Limits of the Criminal Law: Harm to Others* (OUP, 1997).

141 L 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* 8, 3.

142 R Gillon, 'Why Charlie Gard's parents should have been the decision-makers about their son's best interests' (2018) 44 *J Med Ethics* 462.

understanding why those who support the introduction of the significant harm threshold often refer to 'parental autonomy' rather than 'parental rights'.[143] The distinction between these two labels is indicative of two schools of thought. One seeks to promote the decision-making authority as a natural extension of freedoms enjoyed by virtue of being a parent. The other is rooted in rights being granted by the state and remaining subject to the state's oversight.

Taking parental rights as a series of liberties could lead to the conclusion that they are a collective freedom enjoyed by the parents to decide the treatment that their child should be given. But 'in the case of children, misapplied notions of liberty are a real obstacle to the fulfilment by the State of its duties'.[144] If parental autonomy were to continue to be regarded as an exercise of duty to the child, it should continue to be subject to scrutiny and interference when it is determined to be excessively or negligently exercised. The current best interests standard sets a positive, aspirational threshold for the exercise of parental responsibilities by promoting the course of action that is the most beneficial to the child.

On the other hand, the significant harm test sacrifices some of this benefit to the child so as to provide room for the parents' individual wishes. This, however, would run ostensibly contrary to the purpose of the decision—that is to benefit the child—because the decision is taken not on the basis of what is best for the child, but on the basis of what is merely sufficient. In other terms, whereas the best interests approach advocates for the optimum decision, the significant harm threshold reduces the level of protection available by explicitly accepting some level of harm as part of the decision.

143 D Wilkinson & J Savulescu, 'After Charlie Gard: Ethically Ensuring Access to Innovative Treatment' (2017) 390 *Lancet* 540.

144 JS Mill, *On Liberty* (first published 1859, New York, Dover Publications, 2002), pp 88-89.

Where the issue lies is not in the apportionment of decision-making authority but in the common (mis)understanding of the law. Medical interventions are ultimately exercises in mitigation. A course of treatment offered to a child desperately in need of assistance is so offered to mitigate the effects of the condition that requires treating. Thus, when reference is made to that child's 'best interests', 'best' is often no more than a comforting euphemism, in the same way 'significant' is rarely more than an abstract standard. The significant harm threshold may inadvertently invite a 'negative evaluation of parental behaviour',[145] and where a child suffers severe repercussions because of a parent's decision, this has a 'devastating effect on the well-being of the parents'.[146]

The overriding principle and the first consideration in the Children Act 1989 must therefore not be forgotten. The 'child's welfare shall be the court's paramount consideration'. [147] This thesis does not propose a complete defence of the best interests assessment nor suggest that it is without its flaws, but when the task is to consider the welfare of the child above all else, it should not be done by reference to a threshold which gambles protecting the child's welfare against the fragility of the parents'. Introducing the significant harm test would not remedy the concern that decisions are dependent on the morals and value judgments of the decider. Its introduction would, conversely, expose the parents to greater peril of personal ill-effects as a result of their parenting being labelled 'significantly harmful', which would risk rendering the already heated decision-making process far more adversarial. Hospitals would be required to pre-empt challenges from parents who are convinced that the law's greater deference to their views makes their decisions

145 G Birchley, 'The harm threshold and parents' obligation to benefit their children' (2016) 42 *J Med Ethics* 2, 123.

146 ibid.

147 Children Act 1989, s 1(1).

medically correct. Charlie's 'fight' should caution against employing this threshold, lest the process become more public, more personal, and untenably less about the welfare of the child.

Conclusion

The law in relation to children has undergone a series of landmark shifts which have resulted in the positioning of the child as an individual rights-holder with interests separate from those of their parents. Developments such as these abandoned the primitive basis of ultimate paternal authority which stunted the progression of child protection laws and moved towards shared parental responsibilities exercised in the child's interests. Consequently, the child is now seen as a vulnerable legal person to be protected by the parents and the state rather than as a chattel of the patriarch.

Many of these developments were codified in the CA 1989. The chapter noted, however, that this legislation missed an opportunity to make provisions in relation to children's medical treatment after the *Gillick* judgment. What the CA 1989 does provide general guidance on is the role played by the courts in resolving intractable disputes between the parents of a seriously ill child and the healthcare professionals charged with treating them. Analysis throughout the chapter showed that the courts have repeatedly asserted their jurisdiction in these matters as part of their public duty to protect the vulnerable and have since 1989 accorded even greater protection to the welfare of the child through the application of the best interests test. Attempts to guarantee the protection of the child's welfare have been inconsistent but have nonetheless garnered similar results, often in accordance with the presumption in favour of life, save for where continued living would be undesirable and dolorous for the child. Such an inconsistent approach has been highlighted as the main concern in England and Wales and the causes of this inconsistency, alongside proposals to remedy it with the principle of human dignity, will be addressed in Chapter IV using the discussion in Chapter II as a guide for how best interests assessments can be better understood.

The two polarities of parental choice were explored through analysis of *Gard* and *E*, exploring how the courts deal with instances where the parents oppose and propose the withdrawal of treatment, respectively. It used these cases to inform a brief discussion on proposals to introduce a significant harm test, concluding ultimately that applying the test would have produced no positive outcome in either case. Engagement with the language of the judgments and a practical analysis of the significant harm test showed that calls for its implementation into the medical law context are effectively a means of according greater decision-making authority to the parents. Largely this is to legitimise a decision-making process with which many have become disenfranchised because of the tendency for the courts to decide accordingly with medical opinion rather than that of the parents. Unfortunately, this does not solve the problem: it merely replaces it with another.

Chapter IV

Domestic and international children's rights and the value of dignity

Wenn man alle Gesetze studieren sollte,
so hätte man gar keine Zeit, sie zu übertreten.
Johann Wolfgang von Goethe[1]

Introduction

England and Wales and Germany share the central idea that the parents should be able to make decisions for their children as free from state intervention as is possible, but provide for this through different frameworks. The UNCRC represents arguably the most significant common ground in children's rights between the two.[2] This chapter will consider the interactions between the UNCRC and domestic laws, focusing on the extent to which the UNCRC has been implemented into national law frameworks and how obligations towards children's rights under the UNCRC are interpreted. Despite having signed and ratified the UNCRC, England and Wales and Germany implement it by different means with different linguistic formulations that produce diverse responses to the same international instrument. This chapter will consider how the UNCRC influences the decision-making process and how it provides the impetus for protecting and promoting children's rights. It will then go

1 JW von Goethe, 'Erfahrung und Leben' in *Einzelnheiten, Maximen und Reflexionen* (first published 1833, Bd 12, Hamburg, Christian Wegner Verlag, 1953), p 544.

2 United Nations Convention on the Rights of the Child (1989) A/RES/44/25, henceforth 'UNCRC'.

on to consider the relationship between the principle of human dignity and children's rights protection frameworks.

Currently, Germany is in the process of introducing legislation[3] which would embed fundamental principles of the UNCRC—including the importance of the child's best interests—within the existing remit of Article 6 *Grundgesetz*.[4] These proposed changes are intended by the *Bundesregierung* to make children's rights 'more visible'[5] and echo the goal of the UNCRC to 'emphasise the importance of children's rights'.[6] They would also frame the protection of children's rights as positive duties upon the state to guarantee and to protect them rather than negative duties simply not to infringe them. Notably, however, the German amendments are worded differently from the original form in the UNCRC in a way which may affect the level of protection afforded to children's rights.[7] This chapter will assess the potential amendments to Article 6 *Grundgesetz* and how a constitutional anchoring of the

3 Notably, Germany is not the first to seek to recognise children's rights at the constitutional level. For example, Article 39(4) of the Spanish Constitution provides that 'children shall enjoy the protection provided for in the international agreements which safeguard their rights'. Ireland has recognised children's rights at the constitutional level: see C McGing, 'The Children's Referendum 2012' (2014) 29 *Irish Political Studies* 3, 471. South Africa has also made children's rights part of its fundamental legal order: see U Kilkelly & T Liefaard, 'Legal implementation of the UNCRC: lessons to be learned from the constitutional experience of South Africa' (2019) *De Jure Law Journal* 521.

4 If successful, the amendment would add the following to Article 6. 'The constitutional rights of children, including their right to develop as responsible individuals must be respected and protected. Children's best interests must be taken into account in an appropriate manner. The constitutional entitlement of children to a fair hearing in front of the law must be ensured. The primary responsibility of parents shall remain unaffected.'

5 *Bundesregierung*, 'Children's rights to be enshrined in the Basic Law' (2021), available at <www.bundesregierung.de/breg-en/news/rights-of-child-in-basic-law-1841338>, last accessed 25 August 2021.

6 UN Committee on the Rights of the Child, 'Concluding Observations: Germany' (1995) CRC/C/15/Add.43.

7 The proposed bill would require that best interests are 'taken into account in an appropriate manner', whereas the UNCRC declares that these are a 'primary consideration'.

child's best interests and the concept of *Kindeswohl* may impact parents' abilities to make decisions regarding the medical treatment of their children.

As regards England and Wales, the chapter will consider the long-established paramountcy principle as the guiding ethos in determining medical treatments for children. Set against the UNCRC 'primary consideration' principle, the paramountcy principle appears *prima facie* to offer greater protection to children's rights. The chapter will discuss the differences between the established English law approach and the standard set out in the UNCRC with a view to determining how, if at all, a paramount consideration differs from a primary consideration.

Having explored the differing attitudes towards protecting and realising children's rights, the chapter will move onto discuss the specific interest of human dignity. In Germany, human dignity acts as the organising foundational principle of the *Grundgesetz* and is a crucial consideration within the best interests assessment that the state is required to guarantee in all areas of life. It includes, but is not limited to, the individual exercise of self-determination as well as the protection of the right to life itself. Dignity functions in that respect as a lens through which these constitutional rights can be interpreted and also as the principle upon which decisions regarding those rights can be taken. In light of this, the chapter will consider how German law has addressed children's best interests through the lens of human dignity before reflecting on the opportunities to consider dignity in English case-law which have been missed.

The centrality of children's best interests under the UNCRC

Background to the UNCRC

Ratified by all eligible UN member states with the exception of the United States,[8] the UNCRC is the main international law authority on children's rights.[9] It can be traced back to an initial declaration of children's rights in 1924,[10] before a 'lengthy gestation process'[11] which delayed the drafting of the UNCRC until 1979.[12] Yet in spite of the 65 years between the 1924 declaration and the UNCRC's completion, the UNCRC provides only a minimal framework for the rights it contains. Owing to its application in areas of the world with vastly different legal and cultural norms, the drafting of the UNCRC was required to take a consensus-based approach, resulting in a non-specific, at times ambiguous enumeration of children's rights. It is nonetheless regarded as the first time where the child is constructed as a 'principal' or an individual with their own rights,[13] rather than merely the subject of 'concern or an object of intervention'.[14] However, the result of the consensus-based approach is that the broad range of rights it seeks to protect is imprecisely defined and open

8 In 1995, then-US Secretary of State Madeleine Albright signed the UNCRC but President Clinton did not submit it to the Senate for ratification. At the time of writing, the UNCRC is still to be submitted for Senate ratification, even after the Obama administration admitted that it was 'embarrassing'.

9 G van Bueren, 'Children's Rights' in D Moeckli, S Shah, S Sivakumaran, & D Harris (eds), *International Human Rights Law* (3rd edn, OUP, 2018), p 326.

10 D Marshall, 'The Construction of Children as an Object of International Relations: The Declaration of Children's Rights and the Child Welfare Committee of the League of Nations 1900-1924' (1999) 7 *International Journal of Children's Rights* 2, 103.

11 M Freeman, 'Children's Rights as Human Rights' in J Qvortrup, WA Corsaro, & M-S Honig (eds), *The Palgrave Handbook of Childhood Studies* (London, Palgrave, 2009), p 382.

12 ibid.

13 MS Pais, 'The United Nations Convention on the Rights of the Child' (1992) 91 *Bulletin of Human Rights* 2, 75.

14 M Freeman (n 11), p 383.

to interpretation. Furthermore, it is impossible to bring a standalone claim under the UNCRC (in the way one might petition the ECtHR under the ECHR) because the UNCRC lacks a purpose-made enforcement mechanism.[15] By and large, the only substantive guidance available is the generic principle that international treaties are to be interpreted in line with the tenets of international law and compatibly with domestic law, provided that the two do not conflict.[16] Aside from this, the UNCRC's 'enforcement procedures are too weak'.[17] Consequently, the rights under the UNCRC are effectively unenforceable, save for the remedies made available in domestic implementations. Lundy, Kilkelly, and Byrne propose that, 'if its potential is to be fully realised', law- and policy-makers must introduce 'systematic children's rights training and a robust infrastructure designed to monitor, support and enforce implementation'.[18]

Many of the rights relevant to this thesis fall under the heading of 'development' and include the right of the parent to provide direction and guidance to the child;[19] the child's right to be cared for by their parents;[20] the right to be raised by both parents; [21] and the right to periodic review of treatment. [22] The child is also

15 See, eg, CRAE, *Children's Rights in the Courts* (2012), available at <www.crae.org.uk/media/26279/childrens-rights-in-the-courts.pdf>, last accessed 25 August 2021.

16 See, eg, *BVerfGE* 4, 157 (168).

17 A Bissett-Johnson, 'What Did States Really Agree To? Qualifications of Signatories to the United Nations Convention on the Rights of the Child' (1994) 2 *International Journal of Children's Rights* 4, 399.

18 L Lundy, U Kilkelly, & B Byrne, 'Incorporation of the United Nations Convention on the Rights of the Child in Law: A Comparative Review' (2013) 21 *International Journal of Children's Rights*, 442.

19 Article 5 UNCRC.

20 ibid, Article 7.

21 ibid, Article 18.

22 ibid, Article 25.

guaranteed the right to life, survival and development;[23] the right to health and access to health-care services;[24] and the right to a decent standard of living.[25] Comparisons may be drawn between the rights under the UNCRC heading of development and the rights contained within the *Grundgesetz*[26] and the Children Act 1989.

More generally, the UNCRC also seeks to raise awareness of children as a class of legal persons[27] so as to avoid situations where there is an unfair conflict between children's and parental rights, which are posited as conflicting, and where 'the battle has been fought on ground selected by the adults'.[28]But the UNCRC is not unrealistic: it recognises that children remain vulnerable,[29] and for this reason it imposes the requirement that 'in all actions concerning children [...] the best interests of the child shall be a primary consideration'.[30] However, the definition or interpretation of 'best interests' will change between different nations and cultures, leading some, such as Mnookin, to conclude that 'deciding what is best for a child poses a question no less ultimate than the purpose and value of life itself'.[31] No jurisdiction has attempted to precisely define best interests: instead, they act as the ultimate flexible tool for determining medical treatment.

23 ibid, Article 6.
24 ibid, Article 24.
25 ibid, Article 27.
26 Article 6(2) *Grundgesetz*.
27 M Freeman (n 11), p 377.
28 *R (Williamson) v Secretary of State for Education and Employment* [2005] 2 FLR 395 (Lady Hale).
29 JC Murphy, 'Rules, Responsibility and Commitment to Children: The New Language of Morality in Family Law' (1999) 60 *University of Pittsburgh Law Review* 1128.
30 Article 12 UNCRC.
31 R Mnookin, 'Child—Custody Adjudication: Judicial Functions in the Face of Indeterminacy' (1975) 39 *Law and Contemporary Problems* 3, 226.

For that reason, the Convention acts as 'a beginning rather than the final word on children's rights'.[32] As such, individual nations must look to their own domestic legal frameworks for the answers. In England and Wales, this is found largely in the jurisprudence of the courts in the form of the paramountcy principle; in Germany, it is found in the provisions of Article 6(2) *Grundgesetz* and their subsequent interpretation by the courts, including the *Bundesverfassungsgericht*.[33]

The paramountcy principle in light of the UNCRC and the ECHR

The paramountcy of the child's welfare and best interests is a long-established principle in English law, appearing first in the Guardianship of Infants Act 1925. Its wording has changed little from when it was incorporated into the Guardianship of Minors Act 1971 [34] and subsequently into the Children Act 1989. [35] What is noteworthy besides this is that the principle has been consistently restated at the beginning of each Act, reflecting perhaps a strong and unwavering commitment within domestic law to protect the welfare of children. The principle also makes specific reference to the courts' obligations as, in proceedings concerning children, 'the court [...] shall regard the welfare of the infant as the first and paramount consideration'.[36]

Despite its wording having barely changed over the past century, its meaning has not always been conclusive and its implementation has not always been consistent.

32 M Freeman (n 11), p 388.

33 *'Pflege und Erziehung der Kinder sind das natürliche Recht der Eltern und die zuvörderst ihnen obliegende Pflicht. Über ihre Betätigung wacht die staatliche Gemeinschaft.'* The approach under Article 6(2) *Grundgesetz* may be regarded to be a reaction to Naziism, in that it leaves the determination of how individuals should be raised to the parents rather than investing the state with this power.

34 Guardianship of Minors Act 1971, s 1.

35 Children Act 1989, s 1(1).

36 Guardianship of Infants Act 1925, s 1(1).

This has led to the same principle being the justification for a number of decisions which do not adequately reflect the level of protection that would be expected from a 'paramount consideration'. Such justifications are made in line with the paramountcy principle as influenced by the seminal[37] case of *J v C*,[38] which has been reaffirmed in subsequent case-law as the appropriate approach to be taken.[39] Lord MacDermott's formulation of 'paramount' as 'overriding' has thus prevailed. He described

> 'a process whereby, when all the relevant facts, relationships, claims and wishes of parents, risks, choices, and other circumstances are taken into account and weighed, the course to be followed will be that which is most in the interests of the child's welfare. That is [...] the paramount consideration because it rules upon or determines the course to be followed'.[40]

Lord MacDermott developed this narrow, welfare-first conception of the paramountcy principle a decade before the naissance of the CA 1989, with the House of Lords rejecting in *J v C* the possibility that welfare be merely one—or, alternatively, a 'primary'—consideration among others. The approach was approved as having been 'stated with clarity and precision by Lord MacDermott and will be in the mind of every judge who tries an infant case'.[41] Following the coming into force of the CA 1989, the same approach continued to be applicable,[42] with the

37 H Reece, 'The paramountcy principle: Consensus or construct?' (1996) 49 *Current Legal Problems* 1, 267.

38 [1970] AC 668.

39 See, eg, *Re O (Contact: Imposition of Conditions)* [1995] 2 FLR 124, 128; *Re W (Children)* [2012] EWCA Civ 999.

40 *J v C* [1970] AC 668, 710 (Lord MacDermott).

41 *Re K (Minors) (Children: Care and Control)* [1977] Fam 179, 183.

42 *Re O & Anor (Minors) (Care: Preliminary Hearing)* [2004] 1 AC 523, at [24].

child's welfare continuing to be the determinative factor, rather than merely one factor among others to be considered,[43] though this was more a consequence of the pre-existing case-law than it was the new statutory frameworks. Nonetheless, the child's welfare enjoys protection in two layers, with a statutory guarantee and with a judicial commitment to prioritising the welfare of the child over all other concerns in a case.

Judicial prioritisation of the child's interests through the paramountcy principle has previously led to the courts overriding parental decisions. Lord Oliver legitimised this capability of the courts by describing decision-making as a 'privilege' of parenthood that was

> 'circumscribed by many limitations imposed both by the general law and, where the circumstances demand, by the courts or by the authorities upon whom the legislature has imposed the duty of supervising the welfare of children and young persons'.[44]

He was nonetheless loath to claim an absolute decision-making authority on behalf of the court, electing instead to emphasise that the court's intervening upon these decisions does not 'terminate' parental responsibility. Rather, Lord Oliver contextualised the consequence of the court's intervention as one where the parents' responsibilities and decision-making authority should 'become immediately subservient to the paramount consideration which the court has always in mind, that is to say, the welfare of the child'.[45]

43 N Lowe & G Douglas, *Bromley's Family Law* (11th edn, OUP, 2015), p 414.

44 *Re KD (Minor) (Ward: Termination of Access)* [1988] AC 806, 825 (Lord Oliver). See also *Re MA & Ors (Children)* [2009] EWCA Civ 853; *Re EV (A Child)* [2017] UKSC 15.

45 ibid.

Subsequently, the courts have elucidated a concept of subservience which gives rise to a hierarchical conceptualisation of rights and interests where those of the child are isolated and considered separately from those of the parents.[46] Consequently, the parents' rights and responsibilities are not only superseded by the child's interests and reduced to a less-than-paramount consideration but are then required to be exercised in line with the interests that supersede them. This exercise can sometimes require the parents to set aside their own opinions and act in compliance with the 'outcome that was evidentially proven to promote [the child's] welfare'.[47] Conveniently, this may also be viewed as the English law equivalent of the *dienende Rechte* conceptualisation of parental rights explored in Chapter III regarding Germany.

Any such hierarchical structuring of these rights is dependent on their being separated and clearly demarcated as being different, but not necessarily competing, rights. As a matter of phenomenon this is not always guaranteed and the history of the paramountcy principle's implementation would seem to fall in line with this. Crucial to the proper functioning of the paramountcy principle is the principle of individualism, though its efficacy is diminished when interests of other parties—oftentimes the parents—are incorporated into a general declaration of the child's best interests. *Raqeeb* [48] and the earlier case of *Re E* [49] each show that these

46 J Eekelaar, 'Beyond the welfare principle' (2002) 14 *Child and Family Law Quarterly* 3, 237.

47 S Choudhry & H Fenwick, 'Taking the rights of parents and children seriously: Confronting the Welfare Principle under the Human Rights Act' (2005) 25 *OJLS* 3, 461. See also Herring, 'The Human Rights Act and the Welfare Principle in family law—conflicting or complementary?' (1999) 11 *Child and Family Law Quarterly* 3, 223.

48 *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin), [2019] EWHC 2530 (Fam).

49 *Re E (Residence: Imposition of Conditions)* [1997] 2 FLR 638, not to be confused with *Cambridge University Hospitals NHS Foundation Trust v Mother of E & Anor* [2021] EWHC 126 (Fam) which was discussed in Chapter II.

assessments can be impacted when the parents align their own interests with the child's or when the child's best interests, as in *Raqeeb*, are taken to be aligned with those of their parents. Oftentimes this happens for reasons which are understandable but nonetheless run contrary to the premise that the child's interests take precedence *simpliciter* over the interests of all other parties. The outcome in *Re E*, for instance, was possible only where the assessment of the child's best interests was influenced by, and incorporated, the mother's interests. Similar conclusions can be drawn of *Raqeeb*, where religion was given disproportionate importance in the assessment of a four-year-old child's best interests.

As a result of this, children's interests are not viewed in isolation as the principle would suggest, but through the lens of the competing interests of parents and HCPs.[50] What is on paper a highly abstract consideration—that is the determination of what are *truly* the child's best interests—becomes reduced to a binary consideration between two opposing ideas. Little regard is given to the middle-ground between the two, where perhaps a better and more equitable formulation of the child's best interests lie. This polarised approach is an undesirable and inevitable repercussion which arises typically from a dispute between the parents and the HCPs, where each side approaches the issue with differing views. Augmenting the already high levels of conflict in these hearings shifts the focus from the child's interests to pacifying the opposing sides.[51] But this conflict should not exist, for the parents' decisions vis-à-vis the child should not be influenced by individual views which do not serve the child's interests. Perhaps this conflict exists because of a lack of a principled basis upon which these decisions can be based renders the subjective best interests standard open to challenge. Thus, the conclusion of what constitutes

50 Herring (n 47).

51 The new developments in Germany, discussed later in this chapter, recognise the importance of the input of the child and the role to be played by the child.

the child's best interests may perhaps be viewed more accurately as the resolution of a dispute between the parents and HCPs in which the child is imputed with supposed views that they may not hold. The child's interests act as a conduit for an interested party's view to be advanced.

In light of this, it is difficult to view the child's welfare as 'paramount' or indeed as anything other than 'watered down'.[52] Accordingly, the logical next step is that the paramountcy principle in English law may amount to no more than one consideration amongst others with no real significant importance which fails to give the child's interests the level of impetus they should receive. Yet, given that the UNCRC requires only that children's interests are to be the 'primary consideration',[53] the less-than-desirable diluted paramountcy approach appears to satisfy and, perhaps even still, go beyond the requirements of the UNCRC.

As such, the shortcomings of the paramountcy principle in England and Wales can still be regarded as the relative gold-standard under the UNCRC. Regrettably, however, the principle falls short. At best, the paramountcy principle is one of the child's best interests being a *primary* principle, with the subsequent decision masquerading as being made under the guise of the child's interests being paramount. What is clear from any discontent one may have with the performance of the English law principle is that an ineffective standard open to such potential manipulation cannot reasonably be the standard aspired to by an international convention which seeks to elevate the importance of children's rights. If 'paramountcy' is to be taken as a step beyond 'primacy' in terms of protecting rights, the question becomes one of how England and Wales's approach goes beyond

52 J Eekelaar, 'Beyond the welfare principle' (2002) 14 *Child and Family Law Quarterly* 3, 237.

53 Article 3(1) UNCRC.

'primacy' to give true 'paramount' protection. One may ask further whether there is a difference between 'primary' and 'paramount' and, if there is, whether it even matters.

Possibly, there is no difference between the two because the decisions are patient-centric, individual,[54] and often subjective. Given that there is little to no guidance on how the paramountcy or primary principles should be applied, it may well be anyone's guess as to which has been used in any given case. Decisions which claim to have taken the child's best interests as the paramount consideration but have nonetheless incorporated the parents' interests into that assessment have, in reality, conducted an assessment based on the primary principle. Indeed, the rationale of the primary principle—that the child's best interests are the first consideration among others—forms part of the paramountcy principle, with the difference being that the latter attributes greater weight to those interests. Again, this is a matter of subjectivity: the level of weighting that, eg, one judge considers to be 'paramount' may not reach the same standard in the opinion of another judge.

Notwithstanding semantic debates, the issue of weighting the child's interests becomes more of an issue when one considers the level of involvement required from individual states under the UNCRC in light of obligations under other conventions.[55] Some, such as Kilkelly, lament that the ECHR seemingly does not

54 See, eg, *Re S (Adult Patient: Sterilisation)* [2001] Fam 15, quoted by Lady Hale in *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [24].

55 In the context of the ECHR, see J-F Akandji-Kombe, 'Les obligations positives en vertu de la Convention européenne des Droits de l'Homme' (Belgium, 2006), p 5, available at <https://rm.coe.int/168007ff61>, last accessed 20 June 2021. Since *Belgian Linguistic (No. 2)* (1968) 1 EHRR 252, the ECtHR has recognised some positive elements to the ECHR rights which serve as a 'decisive weapon' to facilitate the effectiveness of the rights. See J-P Marguénaud, *La Cour européenne des Droits de l'Homme* (Collection Connaissance du droit, Paris, 2nd edn, Dalloz, 2002), p 36.

require states to provide 'even the most basic recognition of the child'.[56] Meanwhile, the UNCRC is described as 'an important and easily understood advocacy tool' which 'promotes children's welfare as an issue of justice rather than one of charity'.[57]

Insofar as it is a 'tool', the UNCRC functions as a driver of change which sets out the means by which individual nations may recognise and protect children's rights, but nonetheless requires positive action from states party to implement its terms and to achieve these aims. The difficulties of this seemingly straightforward task shall be explored shortly, but one's initial impression may be that requiring positive action would strengthen the protection afforded to children's rights. Again, however, the semantic and functional ambiguities stemming from what 'primary consideration' is to be taken to mean frustrate this. These difficulties become compounded when, in line with their international obligations, states must incorporate these ambiguities into their domestic law. Theoretically speaking, the UNCRC would permit England and Wales to 'children's rights-proof'[58] its domestic legislation, but it is unclear how the UNCRC should be implemented, given that the existing levels of protection under the paramountcy principle appear to go further than the UNCRC's requirements. It is also difficult to understand what 'children's rights-proof' means when the UNCRC is inconveniently mute on the issue of best interests.

Perhaps the procedure of making domestic legislation 'children's rights-proof' is a more abstract exercise and one achieved through awareness rather than action. Fortin's view is that, through instruments such as the UNCRC, children's rights gain

56 U Kilkelly, *The Child and the European Convention on Human Rights* (2nd edn, Routledge, 2016), p 4.

57 P Veerman, *The Rights of the Child and the Changing Image of Childhood* (Dordrecht, Martinus Nijhoff, 1992), p 184.

58 U Kilkelly & L Lundy, 'Children's rights in action: using the UNCRC as an auditing tool' (2006) 331 *CFLQ* 32.

an 'international dimension which is difficult for national governments to ignore'.[59] Certainly, as the most widely ratified human rights treaty, the UNCRC provides children's rights with an international reach wider than, for example, the ECHR,[60] yet this is scarcely an achievement given that the ECHR is explicitly European versus the UNCRC's global application. Such wide reach of the UNCRC could naturally be assumed to translate into an equally wide implementation and respect for children's rights. Ideally, this would be the case. It does not appear to be entirely true in practice, however. For example, through consistent failure to ratify it, the United States has, since 1995, effectively ignored the existence of the UNCRC and the rights it confers to children. In English law, the UNCRC has been reduced to a footnote in the already existing children's rights protection frameworks because the paramountcy principle appears to offer greater protection than the 'primary consideration' requirement under the UNCRC. Despite the arguments of Kilkelly *inter alia* that more profound judicial engagement with it would reinforce the protection of rights in the domestic context,[61] the UNCRC has received relatively little attention in domestic law as a consequence of the paramountcy principle and its long-established line of jurisprudence.[62] Given that the English law weighting of children's best interests was already greater than that under the UNCRC, ratification may potentially be no more than a symbolic gesture. The two are agreed on the idea that the child's best interests should take precedence, but what is lacking is a clear principle by which that can be given effect. Human dignity may provide the answer

59 J Fortin, 'International children's rights' in J Fortin (ed), *Children's rights and the developing law* (3rd edn, CUP, 2021), p 58.

60 S Bissell, 'Overview and implementation of the UN Convention on the Rights of the Child' (2006) 25 *Lancet* 689.

61 U Kilkelly, 'Best interests of the child: A gateway to children's rights?' in LAB Macfarlane & E Sutherland, *Implementing Article 3 of the UNCRC: Best Interests, Welfare and Well-Being* (1st edn, CUP, 2016).

62 O De Schutter, *International Human Rights Law* (2nd edn, CUP, 2017), pp 280-294.

and its universality may work well alongside the UNCRC's attempted universal application.

The *Grundgesetz* and implementation of the UNCRC in Germany

Germany signed the UNCRC in 1990 and ratified it later in 1992,[63] at which point it became part of the German legal system like any other domestic law.[64] With a status equivalent to federal law,[65] the Convention takes precedence over individual laws of the *Länder* and over other laws and regulations which would normally be subordinate to the German federal law.[66] Though superior to *Landesrecht*, the Convention remains nonetheless subordinate to the *Grundgesetz*. In practice, German jurisprudence recognises that international human rights treaties must be taken into account and given elevated importance in the interpretation of fundamental rights,[67] even though there is no requirement that the UNCRC be implemented at a (quasi-)constitutional level.[68] The UN Committee on the Rights of

63 A list of participants and signatories of the UNCRC is available in the online UN Treaty Database, in addition to a list of each participant's declarations and reservations.

64 R Geiger, *Grundgesetz und Völkerrecht* (6th edn, CH Beck, Munich, 2013), p 151; F Wapler, *Umsetzung und Anwendung der Kinderrechtskonvention in Deutschland: Rechtsgutachten im Auftrag des Bundesministeriums für Familie, Senioren, Frauen, und Jugend* (Johannes Gutenberg-Universität Mainz, 2017).

65 Article 59(2) *Grundgesetz*. See also *BVerfGE* 74, 358 (370); *BVerfGE* 82, 106 (120); *BVerfGE* 111, 307 (317); *BVerfGE* 128, 282 (306); *speziell zum Gesetzesrang der Kinderrechtskonvention BVerfG*, 05.07.2013, Az. 2 BvR 708/12, juris Ziff. 21

66 *Grundgesetz*, Art 31: *'Bundesrecht bricht Landesrecht'*. See also S Schmahl, *Kinderrechtskonvention mit Zusatzprotokollen* (Handkommentar, 2nd edn, Nomos, Baden-Baden, 2017), 25.

67 *BVerfGE* 58, 1 (34); *BVerfGE* 59, 63 (89); *BVerfGE* 74, 352 (370); *BVerfGE* 110, 203.

68 E Rossa, *Kinderrechte: Das Übereinkommen über die Rechte des Kindes im internationalen und nationalen Kontext* (2013), p 102. Some countries, including Austria and Spain, have nonetheless done this. See Schmahl (n 66).

the Child has declared that it would welcome constitutional implementation,[69] though this desire faces resistance from some—such as Dederer—who contemplate whether the UN Committee's calls for states to implement the UNCRC at the constitutional level amount to an *ultra vires* exercise of power.[70] In any case, the views of the UN Committee are legally non-binding[71] and as such carry no power whether it be *ultra* or *intra vires*: rather, they are intended to facilitate dialogue with states.[72] The UN Committee is not a committee of legal experts convened to opine on legal matters: rather it is interdisciplinary[73], 'less concerned with formal legal norms than with substantive perspectives and signal effects'.[74] Germany's Federal Ministry of Justice (BMJV) also agrees that there is no obligation to implement the UNCRC at a constitutional level.[75] In place of this obligation, Article 4 UNCRC grants states the ability to determine how they implement the UNCRC in domestic law.[76] What results

69 UN Committee on the Rights of the Child, 'General Comment No 5: General measures of implementation of the Convention on the Rights of the Child' (2003) CRC/GC/2003/5.

70 HG Dederer, 'Kinderrechte auf internationaler und supranationaler Ebene. Bestandsaufnahme und Ausblick' in A Uhle (ed), *Kinder im Recht. Kinderrechte im Spiegel der Kindesentwicklung* (2019), p 306.

71 See *BVerfG*, Urteil v. 24.7.2018 (2 BvR 309/15), where the *Bundesverfassungsgericht* decided so in relation to the UN Convention on the Rights of Persons with Disabilities, its reasoning applying also here.

72 Articles 44 & 45 UNCRC. See also S Schmahl, *Kinderrechtskonvention mit Zusatzprotokollen* (Handkommentar, 2nd edn, Nomos, Baden-Baden, 2017).

73 Article 43 UNCRC. See also G Dorsch, *Die Konvention der Vereinten Nation über die Rechte des Kindes* (1994), p 275; L Krappmann, 'Anspruch und Kerngehalte der Kinderrechtskonvention der Vereinten Nationen' in H Bielefeldt, V Deile, B Hamm, F-J Hutter, S Kurtenbach, & H Tretter (eds), *Jahrbuch Menschenrechte* (Böhlau Verlag, 2010), p 15.

74 S Schmahl, 'Verpflichtet das Völkerrecht zur Einführung von Kinderrechten ins Grundgesetz?' (2020) *Recht der Jugend und des Bildungswesens* 1, 11. A similar approach is reflected in relation to the UN Convention on the Rights of Persons with Disabilities in R Uerpmann-Wittzack, 'Die UN-Behindertenrechtskonvention in der Praxis des Ausschusses für die Rechte von Menschen mit Behinderungen' (2016) 54 *Abgabenverfahren und Rechtsschutz* 181, 211.

75 BMJV, 'Abschlussbericht der Bund-Länder-Arbeitsgruppe „Kinderrechte ins Grundgesetz"' (14.10.2019), p 24; BMJV, 'Referentenentwurf: Entwurf eines Gesetzes zur Änderung des Grundgesetzes zur ausdrücklichen Verankerung der Kinderrechte' (22.11.2019), p 6.

76 J Tobin, 'Article 3' in J Tobin (ed), *The UN Convention on the Rights of the Child* (2019), p 73.

from this is a simple duty that states discharge their obligations as wholly as they are able to given their individual legal and financial arrangements.[77]

Individual states' freedoms to implement the UNCRC within their own domestic frameworks has led to some debate in Germany as to how the UNCRC may be incorporated into law alongside the rights already present under the *Grundgesetz*. Among the arguments against a more formalised implementation of the UNCRC into the *Grundgesetz* is the belief that children's rights are already protected under the wider umbrella of fundamental rights in Germany. This does appear to be true: since 1968, the *Bundesverfassungsgericht* has taken the view that children are fundamental rights holders and are 'beings with their own human dignity and their own right to the development of their personality' in line with, *inter alia*, Articles 1 and 2 *Grundgesetz*.[78] This approach is also taken regarding questions of *Sorgerecht*,[79] and children should be encouraged and permitted to make decisions for themselves where possible for the sake of the development of their personality.[80] Protection is also offered for children's rights in that they are able to be party to disputes in the *Bundesverfassungsgericht* where issues of their fundamental rights are deemed to be relevant,[81] and their rights have horizontal effect against, eg, their parents.[82] To that end, some consider that explicit implementation of parts of the UNCRC which are

77 UN Committee on the Rights of the Child, 'General Comment No 13: The right of the child to freedom from all forms of violence' (2011) CRC/C/GC/13; 'General Comment No 19: Public budgeting for the realisation of children's rights' (2016) CRC/C/GC/19.

78 *BVerfGE* 24, 119 (144); *BVerfGE* 121, 69 (92 f); *BVerfGE* 24, 119 (114 f); *BVerfGE* 133, 59. See also D Reuter, *Kindesgrundrechte und elterliche Gewalt* (Berlin, 1968), p 81.

79 *Sorgerecht* is sometimes translated as 'custody', however its closest English law equivalent is 'parental responsibility', as it is not determined simply by where the child resides but by who has the decision-making authority. See *BVerfGE* 55, 171 (178 f); *BVerfGE* 84, 168 (182 f); *BVerfGE* 99, 145 (157).

80 *BVerfGE* 59, 360 (387) f.

81 *BVerfGE* 72, 122 (132) ff.

82 *BVerfGE* 133, 59 (43).

already regarded as being covered by the *Grundgesetz* may well be no more than symbolic.[83]

Recently, however, the German government has responded to calls[84] for the UNCRC to be directly implemented into the *Grundgesetz*. In January 2021, it published its draft bill on an *ausdrückliche Verankerung* or an 'explicit anchoring' of children's rights into the *Grundgesetz*.[85] If adopted, the changes would modify Article 6(2) and insert a commitment to respect and protect 'the constitutional rights of children, including their right to develop into independent personalities'; to give 'due consideration' to children's best interests; and to uphold the 'constitutional right of children to be heard'.[86] The amendment would, however, not interfere with the parents' primary

83 For instance, Article 2 *Grundgesetz* guarantees the right of free development of one's personality to *all* individuals, whereas under Article 29 UNCRC this right is sought only to be guaranteed for children.

84 See, eg, Wissenschaftliche Dienste des Deutschen Bundestages (WD), 'Aufnahme von Kinderrechten ins Grundgesetz' (30.11.2017, WD 3-3000-226/17); WD, 'Kinderrechte im Grundgesetz—zur Grundrechtsträgerschaft von Kindern' (07.12.2017, WD 3-3000-242/17); WD, 'Zur Aufnahme von Kinderrechten in das Grundgesetz—Gegenüberstellung verschiedener Formulierungsvorschläge zur Verankerung von Kinderrechten in Art. 6 GG' (18.12.2019, WD 3-3000-272/19); WD, 'Zur Aufnahme von Kinderrechten ins Grundgesetz—Gegenüberstellung eines Formulierungsvorschlages mit vier kinderrechtlichen Grundprinzipien der UN-Kinderrechtskonvention' (16.12.2019, WD 3-3000-276/19); WD, 'Sachstand, Kinderrechte ins Grundgesetz—Zum Gesetzesentwurf des Bundesministeriums der Justiz und für Verbraucherschutz' (23.01.2020, WD 3-3000-012/20).

85 BMFSFJ, 'Gesetzentwurf der Bundesregierung—Entwurf eines Gesetzes zur Änderung des Grundgesetzes zur ausdrücklichen Verankerung der Kinderrechte' (19.01.2021), available at <www.bmfsfj.de/resource/blob/165208/189dccd485dd00054ae6ff287d19fcfe/gesetzentwurf-kinderrechte-grundgesetz-data.pdf>, last accessed 26 August 2021.

86 WD, 'Aufnahme von Kinderrechten ins Grundgesetz: Fragen zum Gesetzentwurf der Bundesregierung' (01.02.2021), available at <www.bundestag.de/resource/blob/821650/6e8135b171374754191ed6e161b45a83/WD-3-013-21-pdf-data.pdf>, last accessed 26 August 2021.

responsibilities towards their children, nor would it shift any of their decision-making powers to the state.[87]

The overarching purpose of the constitutional amendments is to clarify the constitutional position of children and of children's rights. They seek to make children's rights 'more visible' and to 'underline the legal status of children and families'[88] whilst simultaneously acknowledging and retaining the 'constitutional weight' of other rights and guarantees under the *Grundgesetz*, including the pre-established principles which underpin the relationships between parents and the state. In that respect, the amendment does not create new rights specifically for children. Rather, it makes reference to existing fundamental rights to clarify the position that children are holders of basic rights, a position which is made clear by the language choice in the amendment which explicitly includes the rights to self-determination and development (found under Article 2) within the constitutional rights held by children. [89] This position was previously taken by the *Bundesverfassungsgericht* in interpreting Articles 1 and 2 *Grundgesetz* for children,[90] but now seems set to move from a principle of jurisprudence to a constitutional absolute.

87 ibid.

88 BMFSFJ, *Gesetzentwurf der Bundesregierung* (19.01.2021) (n 85), 2.

89 *'Die verfassungsmäßigen Rechte der Kinder einschließlich ihres Rechts auf Entwicklung zu eigenverantwortlichen Persönlichkeiten sind zu achten und zu schützen.'*

90 *BVerfGE* 24, 119 (145).

Entrenchment of the *Kindeswohlprinzip*

Aside from clarifying that children are holders of basic rights, the bill seeks to entrench the *Kindeswohlprinzip*,[91] which would require an 'appropriate consideration' to be made of the child's best interests. Furthermore, the constitutional right for the child to be heard in proceedings would be incorporated into the wider remit of the child's best interests, on the premise that 'the best interests of the child can only be adequately decided if the child has been heard beforehand'. [92] The *Bundesverfassungsgericht* has previously declared the child's best interests to be an 'essential component' of the exercise of parental responsibility under Article 6(2) *Grundgesetz*,[93] and so the explicit mention of the *Kindeswohlprinzip* in a revised Article 6(2) would serve to entrench and to reinforce the position taken by the *Bundesverfassungsgericht* up to now. To that end, the factors previously considered in assessments of children's best interests would continue to play an important role,[94] albeit now with the additional requirement that the child be heard as practicably as is possible.

However, the generally imprecise definition of best interests and the wording of the draft sentence have attracted some criticism for being too open to interpretation.[95] As currently formulated, the draft does not name any public or private body—nor

91 *'Kindeswohlprinzip'* can be translated as the 'principle of children's welfare', though it is perhaps better defined as the 'principle of children's best interests'.

92 WD (n 86).

93 *BVerfGE* 133, 59 (77); *BVerfGE* 107, 104 (117); *BVerfG*, 19.09.2006, 2 BvR 2115/01.

94 Deutscher Bundestag, *Definition des Begriffes Kindeswohl* (2021, BT-Drs. 19/23317).

95 M von Landenberg-Roberg, 'Symbolpolitik ohne Kollateralschäden?' *Verfassungsblog* (13 January 2021), available at <https://verfassungsblog.de/symbolpolitik-ohne-kollateralschaden/>, last accessed 26 August 2021; F Wapler, 'Und ewig grüßt das Kindeswohl' *Verfassungsblog* (14 January 2021), available at <https://verfassungsblog.de/und-ewig-grust-das-kindeswohl/>, last accessed 26 August 2021.

even the state—as being obliged to consider the child's best interests. It also does not mention the role of the parents in a constitutionally mandated observation of the *Kindeswohlprinzip*. It is nevertheless possible that prescribing the bodies and individuals responsible for this is unnecessary, given that the *Grundgesetz* already makes it clear that the state has a duty to respect and to protect fundamental rights, and that parents are responsible for their children.[96] Thus any obligation incumbent upon a public authority would derive from the overarching requirement that the state does not violate fundamental rights in the same way that the references to children's rights in the draft amendment are references to rights under the *Grundgesetz* which children already hold. Private bodies, however, are not explicitly designated by the *Grundgesetz* as being required to protect fundamental rights.[97] But this runs contrary to the equivalent formulation in the UNCRC, which states that,

> 'in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration'.[98]

The German formulation also departs from the primary consideration requirement, electing instead to require an 'appropriate consideration' of the child's best interests.[99] Whilst the appropriate consideration standard may *prima facie* offer less

96 Articles 1(3) & 6(2) *Grundgesetz*.

97 Article 1 *Grundgesetz* mandates only that 'the legislature, the executive, and the judiciary' and 'all state authority' are bound by the fundamental rights. As regards parents, it is possible that they may be regarded as indirectly bound by Article 6, including the rights of their children and the duties owed to them by the parents. They may also be bound to observe the fundamental rights of children, in a non-legal sense, by the possibility that, if they were to act in contravention of those rights, the state would be obliged to intervene.

98 Article 3(1) UNCRC.

99 BMFSFJ, *Gesetzentwurf der Bundesregierung* (19.01.2021) (n 85).

protection to children's rights than the English law paramountcy principle—and perhaps even the UNCRC primary consideration principle—it is best viewed as a pragmatic response to Germany's unique constitutional landscape. This arrangement, which is communitarian in nature, [100] necessitates a nuanced approach to balancing the rights of the child with those of others concerned. The suitability of such a consideration being 'appropriate' ultimately depends on how 'appropriate' is defined. If it were to be defined by reference to a case—that is to say the standard of consideration is dependent upon the individual facts of the case and the impact of those facts upon the child—then this would arguably be more sustainable an approach than if it were to be defined by reference purely to the decider's perception of what is appropriate.[101]

Whether the definition of 'appropriate' would become a problem would depend largely on how the *Bundesverfassungsgericht* interprets the new formulation of Article 6 and the differences between an 'appropriate' consideration and a *vorrangiger Gesichtspunkt*:[102] a 'priority' or 'paramount' consideration. The view of the *BMFSFJ* is that, in the context of the German constitutional arrangements, 'the concept of appropriateness fits better into the existing doctrine of fundamental rights'. [103] Hölscheidt agrees with this, arguing that a requirement of a paramount consideration may raise question over whom or what the child's best interests must

100 In *BVerfGE* 30, 173, the *Bundesverfassungsgericht* framed this in the context of 'an autonomous person who develops freely within the social community'. See also *BVerfGE* 45, 187 [227].

101 Consider, for example, the importance attached to religion in *Raqeeb* compared with how the parents' religious views had been dealt with in other cases. The level of consideration of religion deemed 'appropriate' in *Raqeeb* was sufficient to change the outcome of the case fundamentally.

102 As in BMFSFJ, *Gesetzentwurf der Bundesregierung* (19.01.2021) (n 85). The German literature differs on how it interprets *'vorrangig'*: some take it to mean 'paramount', whereas others take it to mean 'priority'.

103 BMFSFJ (n 88).

be considered against and 'what rank it is at all'.[104] In that respect, the requirement of an appropriate consideration rather than a paramount consideration avoids creating the impression that children's fundamental rights are 'trump cards'.[105] It fits with the intention of the *Bundesregierung* that reforms to Article 6 *Grundgesetz* are designed to increase the visibility of children's rights, not to create new rights exclusively for children which shift the balance in the parent-child-state relationship.[106]

It is also possible that the *Bundesregierung* has proposed only an appropriate consideration requirement in deference to the long-established proportionality approach of the *Bundesverfassungsgericht*. In this regard, 'appropriate' may not be intended to create or impose a standard: rather it may be intended solely to provide the *Bundesverfassungsgericht* with the means to develop the *Kindeswohlprinzip* in line with its existing jurisprudence,[107] using appropriateness as a sliding scale as part of the wider proportionality analysis. Per von Landenberg-Roberg, the welfare of the child can therefore only be given 'absolute priority as an outflow of the child's personal rights' when 'reference is made to the indispensable basic condition for a healthy child's development of their personality'.[108] von Landenberg-Roberg then acknowledges the potential for the *Bundesverfassungsgericht* to adopt a sliding scale approach to appropriateness which is capable of reaching the paramountcy standard, stating that, when the basic rights of the child are endangered, 'an

104 S Hölscheidt in J Meyer & S Hölscheidt (eds), *Charta der Grundrechte der Europäischen Union* (5th edn, Beck, 2019).

105 von Landenberg-Roberg (n 95).

106 Whilst being a goal of the UNCRC, increasing the visibility of children's rights does not feature as a specific obligation. See Dederer (n 70), p 287. See also G Kirchhof, 'Die Kinderrechte des Grundgesetzes. Sollte die Verfassung zugunsten von Kindern geändert werden?' (2018) *NJW* 2690, 2691.

107 See, eg, *BVerfG*, 05.07.2013, Az 2 BvR 708/12, juris Ziff 21.

108 von Landenberg-Roberg (n 95).

"appropriate" consideration of the child's well-being *requires* its "priority" consideration'.[109] This may well assist in overcoming the difficulties which had previously been encountered as a result of the lack of indication as to how the child's best interests should be interpreted in line with the UNCRC.[110]

But this is more a response to the reality of the law in practice rather than it is a response to the law itself. Under the law, the parents should not be making decisions which run contrary to the child's best interests. In practice, however, the parents may make—knowingly or unknowingly—a decision which produces this effect. Whether this decision is the result of a genuine but misguided desire to do what is right or of a real disagreement with what is happening,[111] the legal and moral duty of parents is, and should be, that they be required at times to set aside some of their own beliefs in order to serve the child's best interests. That is not to say that the child's and the parents' interests are mutually exclusive, though there may be instances where the parents' views on, for example, the efficacy of proposed medical treatment are informed more by hope than by medical evidence and as such require some degree of disengagement. Part of the protections in place for the child's best interests is also to be found in the state's obligation to guarantee the inviolability of human dignity.[112] The potential that the two principles of human dignity and *Kindeswohl* may share the same constitutional arena indicates a strong relationship between the two, with dignity forming the basis for decision-making in the child's best interests.

109 ibid (emphasis added).

110 Schmahl (n 74), pp 9 & 34.

111 cf *Gard*.

112 Article 1(1) *Grundgesetz*.

Dignity as part of the best interests equation

Advances in medical science and the technology available to HCPs to treat the seriously ill have not come without producing a long list of ethical and legal obstacles. One such obstacle that these rapid developments have given rise to is the requirement of some form of legal regulation of specific and important bioethical issues. The concept of patient dignity is one such issue.[113] Human dignity acts as the organising concept of the *Grundgesetz* and as a fundamental principle which the state is required to guarantee and protect in all areas of life, including the individual exercise of self-determination and the protection of the right to life. It also lies at the heart of the international human rights framework,[114] with the ECHR (to which England and Wales and Germany are parties) 'considering the UDHR' [115] and committing to upholding the value of dignity.[116] Yet, whilst it forms the basis for international human rights, it remains a concept at once definitive and intangible: oftentimes it is easier to determine that which runs contrary to human dignity than it is to determine what course of treatment is consistent with human dignity. Sometimes, courts will use language of dignity which refers not to the conceptual grounding of rights but, unhelpfully, to subjective feelings of indignity which do not form that conceptual grounding. Nonetheless, dignity has become an important

113 There is some debate as to whether 'dignity', as a concept, can include non-humans. For the purpose of this thesis, 'dignity' is to be taken to mean 'human dignity'.

114 Universal Declaration of Human Rights (adopted 10 December 1948 UNGA Res 217 A(III) (UDHR), preamble & Art 1.

115 Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights, as amended) (ECHR), preamble.

116 See, eg, A Mowbray, 'The European Convention on Human Rights' in M Ssenyonjo & MA Baderin, *International Human Rights Law: Six Decades after the UDHR and Beyond* (London, Routledge, 2010).

aspect of healthcare provision[117] despite remaining a complex, indeterminate idea.[118] Practically, it is defined almost negatively, with the default position being one of assuming that dignity is unthreatened absent undeniable evidence that it is not. Bioethical questions such as this arise but there are no 'generally accepted answers to these questions, just as there is no ethical consensus on how the problems at hand can be solved'.[119]

Partly, this is because there is no clear consensus on what dignity means.[120] Defining dignity has been called a 'semantic problem in technical jargon' [121] but the implications of the answer go further than resolving merely its meaning. Some, such as Hoerster, argue that dignity is an 'empty formula' which offers no arguments in itself, instead being a blank canvas on which decision-makers can base their decisions. [122] This view is shared by Birnbacher, for whom 'there is something theological about the concept',[123] because, 'as with speech about God, when talking about human dignity, the descriptive components of meaning take a back seat to the expressive and appellative components'.[124]

117 Q Guo & CS Jacelon, 'An integrative review of dignity in end-of-life care' (2014) 28 *Palliative Medicine* 7, 931; P Anderberg, M Leep, AL Berglund et al, 'Preserving dignity in caring for older adults: a concept analysis' (2007) 59 *Journal of Advanced Nursing* 635.

118 R Gamlin, 'An exploration of the meaning of dignity in palliative care' (1998) 5 *European Journal of Palliative Care* 187; CS Jacelon, TW Connelly, R Brown et al, 'A concept analysis of dignity for older adults' (2004) 48 *Journal of Advanced Nursing* 76; G Woolhead, M Calnan, P Dieppe et al, 'Dignity in older age: what do older people in the United Kingdom think?' (2004) 33 *Age & Ageing* 165.

119 N Knoepffler, *Menschenwürde in der Bioethik* (Heidelberg, Springer, 2004), p 10.

120 No definition is found in the UN Charter, nor is one found in the UN Declaration of Human Rights or any other international convention.

121 Knoepffler (n 119).

122 N Hoerster, *Ethik des Embryonenschutzes. Ein rechtsphilosophischer Essay* (Stuttgart, Reclam, 2002), p 28.

123 D Birnbacher, 'Menschenwürde—abwägbar oder unabwägbar' in M Kettner (ed), *Biomedizin und Menschenwürde* (Frankfurt, Suhrkamp, 2004), p 249.

124 ibid.

But the lack of a precise definition of dignity may transpire to be a benefit. Former *Staatsminister* and current Vice Chair of the *Ethikrat*, Julian Nida-Rümelin, saw the

> 'normative orientation towards human dignity, towards respect for the individual human being, as the (humanistic) core of the ethos that a democracy supports or should support'.[125]

It is possible that dignity lacks a precise definition because of this 'humanistic core of the ethos'. [126] The Charter of the UN makes reference to a 'belief in the fundamental rights of man, in the dignity and worth of the human personality',[127] with the Universal Declaration of Human Rights stating additionally that 'all people are born free and equal in dignity and rights'. [128] Attempting to define dignity precisely would, consequently, be a task as difficult as it would be unnecessary. Nida-Rümelin's 'humanistic core' interpretation may also provide some insight as to how dignity is viewed in Germany.

125 J Nida-Rümelin, 'Wo die Menschenwürde beginnt' in *Ethische Essays* (Frankfurt, Suhrkamp, 2002), p 405.

126 ibid.

127 This is mentioned in the preamble to United Nations, *Charter of the United Nations and Statute of the International Court of Justice* (San Francisco, 1945).

128 Article 1 Universal Declaration of Human Rights, UNGA Res 217 A(III) (UDHR) (10 December 1948).

The paramountcy of dignity in Germany

Dignity occupies a prominent position within the *Grundgesetz* and, by extension, German society.[129] Its inclusion within the *Grundgesetz* is often considered to be a 'reaction to the Nazi barbarianism', though this characterisation has led some to call for its definition to be limited only to atrocities on a similar scale.[130] Currently, its application is universal and not limited. Dignity has been the deciding principle in cases ranging from welfare provision[131] to the prohibition of laser tag sports under EU freedom of services law.[132] As such, it has been established as a cornerstone of German society which retains the flexibility to respond to changing societal and legal landscapes. On this, Knoepffler considers that there are two elements to the definition of dignity: its meaning in the context of the *Grundgesetz*, and its meaning in terms of its content.[133]

The universality of dignity's application under the *Grundgesetz* echoes Kant's declaration that it is absolute, given that humans do not have a price or an equivalent by which they can be replaced.[134] Under Article 1, 'human dignity shall be inviolable' and the state is required to 'respect and protect it'.[135] By extension, 'the German

129 Human dignity features also in the constitutions of many other European nations, such as Greece, Ireland, Italy, Portugal, Switzerland, Sweden, and Spain. See P Balzer, KP Rippe, & P Schaber, *Menschenwürde vs. Würde der Kreatur. Begriffsbestimmung, Gentechnik, Ethikkommissionen* (Freiburg, Alber, 1998), p 21.

130 H Hofmann, 'Die versprochene Menschenwürde' (1993) 118 *Archiv des öffentlichen Rechts* 3, 353.

131 See, eg, *BVerfGE* 1, 97; *BVerwGE* 1, 159.

132 Laser-tag, the 'acts of simulated homicide and the trivialisation of violence thereby engendered were contrary to fundamental values prevailing in public opinion': Case C-36/02 *Omega Spielhallen- und Automatenaufstellungs-GmbH v Oberbürgermeisterin der Bundesstadt Bonn* [2004] ECR I-9609, [7].

133 Knoepffler (n 119), p 11.

134 I Kant, *Grundlegung zur Metaphysik der Sitten* (Berlin, JF Harknoch Verlag, 1785): *'Was über allen Preis erhaben ist, mithin kein Äquivalent verstattet, hat eine Würde'.*

135 Article 1(1) *Grundgesetz.*

people therefore acknowledge inviolable and inalienable human rights as the basis of every community, of peace and of justice in the world'.[136] It can be regarded in that respect as a paramount consideration, being a 'fundamental principle of the constitution without restriction'[137] at the 'centre of the fundamental rights value order',[138] which is regarded as the 'highest value in the system of fundamental rights'.[139] Gröschner notes the importance of dignity's position in the constitutional order, for

> 'if the principle of the inviolability of human dignity were not at the beginning of a normative constitutional order, it would be a purely descriptive sentence that would contain nothing but the linguistic version of a conceptualisation of humanity'.[140]

Developing this, Gröschner proposes that,

> 'as the initial clause of the *Grundgesetz*, it must therefore be understood as the basic clause formulating its image of man, which is in a normative context and is quite legally relevant in this context, but does not have the status of a legal clause that could directly establish rights and obligations'.[141]

136 ibid, Article 1(2).

137 *VerfGH Berlin*, Beschluss von 12.01.1993—55/92.

138 *BVerfGE* 36, 174 (188).

139 *BVerfGE* 35, 366 (376). See also *BVerfGE* 5, 85 (204); *BVerfGE* 45, 187 (227); *BVerfGE* 6, 32 (36); *BVerfGE* 54, 341 (357).

140 R Gröschner, *Menschenwürde und Sepulkralkultur in der grundgesetzlichen Ordnung. Die kulturstaatlichen Grenzen der Privatisierung im Bestattungsrecht* (Boorberg, 1995), p 45.

141 ibid.

In that respect, human dignity can be viewed not necessarily as a right but as a principled legal ground for rights.[142] Thus, dignity under Article 1 *Grundgesetz* sets out the legal principle from which the rights that follow can be derived and it 'establishes the legal capacity of people as people' and as rights-holders.[143] It is not legally enforceable in the same way the basic rights are, but represents the foundation of those rights. Gröschner is therefore correct in that the principle of human dignity does not in and of itself establish rights and duties, but those rights and duties which are established in the *Grundgesetz* (and, further, in federal law and the law of the *Länder*) are organised by and established upon the foundation of human dignity. Vitzthum argues that dignity's position in the constitutional order protects it from 'purely individualistic-private interpretation as a "suggestion box right"' and from appearing as a 'mere authorisation to "pour out [one's] heart"', with those emotional outpourings being given significant legal weight.[144]

Dignity's reach extends further than a means for grounding and protecting individual rights. It delineates the relationship between the German state and the German people, who 'have a right to social value and respect; therefore, it is contrary to human dignity to make people mere objects of the state'.[145] This applies in judicial proceedings where

142 'Rights imply a respect that places one in the referential range of self and others, that elevates one's status from human body to social being': P Williams, *The Alchemy of Race and Rights* (Cambridge MA, Harvard University Press, 1991), p 63.

143 C Enders, *Die Menschenwürde in der Verfassungsordnung. Zur Dogmatik des Art. 1 GG* (Tübingen, Mohr-Siebeck, 1997), p 502.

144 WG Vitzthum, 'Die Menschenwürde als Verfassungsbegriff' (1995) 40 *Juristen Zeitung* 5, 201. See also *BVerfGE* 5, 85 (205); H Sengelmann, *Der Zugang des einzelnen zum Staat* (Hamburg, 1965), pp 76 & 75.

145 *BVerfGE* 50, 166 (175).

> 'the individual should not only be the object of the judicial decision, but they should have their say before a decision that affects their rights in order to be able to influence the procedure and its result'.[146]

The consequence of this is that, if the individual is unable to participate in the process, their rights and dignity must be upheld nonetheless because 'where human life exists, it has human dignity.[147] The 'objective-legal obligations of all state power to protect human dignity'[148] obliges the state to 'make every effort to avoid possible dangers [...] to recognise them early and to counter them with the necessary constitutional means'.[149] According to Nipperdey[150] and Dürig,[151] dignity is 'an indestructible fact' upon which 'a subjective, or at least an objective, but in any case vulnerable, right insists'.[152] Dürig proposes that it can be based around the human 'spirit'—one's ability to decide freely—or the 'core of their personality' (*'der Persönlichkeitskern'*).[153]

But whether dignity is 'indestructible'[154] or based around a *Persönlichkeitskern*[155] does not assist with defining it. Attempts to define it metaphysically (such as by reference to the 'human spirit' or the individual's personality) are doomed to fail, for assumptions which frame capacity or personality as a requirement for dignity

146 *BVerfGE* 9, 89 (95).
147 *BVerfGE* 39, 1 (41). See also Kant (n 134).
148 *BVerfGE* 49, 89 (132).
149 ibid.
150 HC Nipperdey, 'Die Würde des Menschen' in: FL Neumann, HC Nipperdey & U Scheuner (eds), *Die Grundrechte* (2nd edn, 1954), p 1.
151 G Dürig in T Maurtz, G Dürig et al (eds), *Grundgesetz - Kommentar* (9th edn, 1991).
152 Hofmann (n 130), 353.
153 Dürig (n 151).
154 Hofmann (n 130).
155 Dürig (n 151).

would exclude those who lack capacity at the time of deciding or perhaps never had capacity at all. Under these attempted definitions, dignity may not apply to, for example, children, despite the principle being one of *human* dignity. Clearly, this is untenable. The metaphysical approach may be better articulated as a purely physical approach, in that dignity is grounded not in an individual's ability to decide but simply in the individual themselves. In this way, there are no prerequisites to human dignity besides being human.

What is clear is that the difficulty of defining dignity has not prevented it from becoming the key organising concept of the German constitutional order. Its employment as a lens through which the other rights can be interpreted means that its definition can be adapted to suit the right in question, adding an extra layer of protection to the already paramount rights under the *Grundgesetz*.

Missed opportunities to consider dignity in England and Wales

The understanding of dignity in English law is relatively underdeveloped. Possibly as a result of being 'the (humanistic) core of the ethos' underpinning a democratic society,[156] considerations of dignity in English law cases are at best subsumed into wider assessments of the patient's best interests and are not always explicitly mentioned. Whilst it would be incorrect to say that the courts have not considered dignity in its own right at all—there have been a number of cases, including *Raqeeb*, where the court has given an earnest mention to the patient's dignity—there is yet to be any meaningful judicial engagement with dignity or any real attempt to elevate its importance in the decision-making process.

156 Nida-Rümelin (n 125).

In 2003, Macklin, writing from the American perspective, concluded that 'dignity is a useless concept and can be eliminated without any loss of content'.[157] Macklin's argument can be interpreted in two ways. Either dignity is entirely devoid of utility and should no longer be thought of, or—perhaps more likely—dignity is *already* considered as part of a wider analysis and mentioning it separately would have no meaningful impact on the decision-making process. The argument that dignity can be dispensed with fails to account for the possibility that it already plays an important, albeit silent, influential role within the decision-making process. It is possible that, for instance, judges consider dignity when rendering judgments, but do not give it any special mention because they consider it to be one of many factors in the patient's best interests. This could be seen as the English law manifestation of the 'humanistic core', and as such the argument must be refined from merely considering dignity to considering dignity *explicitly*.

What is meant by considering dignity explicitly is that there is some specific reference made by the courts to a consideration of how human dignity impacts the decision. This goes beyond the example in *Raqeeb* where MacDonald J did consider the 'concept of human dignity as an element of the best interests analysis',[158] but did not fully engage with the role it played within that analysis. However, in *Parfitt*, the judge was concerned with the 'high degree of subjectivity involved in describing someone's life or death as having dignity',[159] declaring no intention to 'presume to adopt some supposedly objective concept of dignity to determine her best interests'.[160] In the surrounding context of objective medical fact, dignity was

157 R Macklin, 'Dignity is a useless concept' (2003) 327 *BMJ* 1419.

158 *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2530 (Fam), [2020] 3 All ER 663, [176] (MacDonald J), quoted in *Parfitt v Guy's and St Thomas' Children's NHS Foundation Trust & Anor* [2021] EWCA Civ 362, [17].

159 *Parfitt*, [49].

160 ibid.

described as a 'subjective and malleable concept',[161] a determination which amounts to no more than the courtroom diplomacy for 'useless', with the same conclusion that it is unsuitable for consideration in the courtroom.[162] Dignity in *Parfitt* was not just disregarded: an effort appears to have been made to discredit it and prevent any further consideration of it. The almost disparaging language of the judgment has the effect of casting it in the same negative light as Macklin's analysis.

However, Pippa Knight's Cafcass representative, Neil Davy, saw this differently. His belief was that dignity should have been considered as a crucial element of the best interests assessment, submitting that 'burdens and benefits […] are both aspects of the principle of respect for the dignity of the individual'.[163] His argument was that the principle of dignity, at heart, demands respect for an 'individual's value as a human being and encompasses both their psychological and physical integrity being deemed worthy of respect', with this principle extending to those who have no awareness of their circumstances.[164] Whilst in *Raqeeb*, the arguments advanced on behalf of the hospital trust—to the effect that it would be detrimental for Tafida to undergo the treatment proposed by her parents notwithstanding the fact that she could feel no pain—were expressed in terms of dignity. In *Parfitt*, the trust's arguments were not presented using the language of dignity. Baker LJ nonetheless kicked the issue of dignity into the long grass, concluding that it was not 'necessary or appropriate on this occasion to embark upon a detailed analysis of the arguments [Davy] deployed'.[165] He further stated that,

161 ibid, [50].

162 Interestingly, Hayden J had already articulated some formulation of dignity, or how dignity should be applied, in *M v N* [2015] EWCOP 76, [72], where he assessed that there is 'an innate dignity in the life of a human being'.

163 *Parfitt*, [98].

164 ibid.

165 ibid, [99].

> 'in a future case, it may be necessary for this Court to address arguments akin to those put forward by Mr Davy about the role played by the concept of dignity in decisions of this sort'[166]

but that this 'necessity does not arise on this appeal'.[167]

The question is, therefore: when will it?

Having been mentioned at multiple times throughout the judgment with references to previous cases such as *Raqeeb,* the concept of human dignity had been gradually repositioned as an element of the best interests assessment which was nonetheless significant enough to be worthy of its own explicit consideration. This was possible given Davy's attempts to advance dignity as an argument. The court was, therefore, in a position to consider dignity both as a feature of the child's best interests and also more generally as a legal principle to ground judgments of best interests. Ostensibly, dignity was discounted because of its indeterminate meaning and requirement of a high degree of subjectivity. Yet this does not follow precedent: the best interests assessment, which is often billed as objective or 'neutral',[168] is largely subjective. But it is not discounted on the basis that it, too, is 'malleable'[169] and therefore 'useless'.[170] Such a double standard should not be entertained by the courts. Human dignity can provide a basis for determining best interests, and more

166 ibid, [100].

167 ibid.

168 R Mnookin, 'Child—Custody Adjudication: Judicial Functions in the Face of Indeterminacy' (1975) 39 *Law and Contemporary Problems* 3, 226.

169 *Parfitt*, [50].

170 Macklin (n 157).

profound engagement with the principle by the court may have resulted in a decision that was more strongly grounded in principle.

Katie Gollop QC defended the court's approach, arguing that, 'wisely, the judge avoided the trap of defining, let alone implementing, what dignity means'.[171] Part of Gollop's reasoning behind calling the decision 'wise' was that dignity, being as subjective as it is, means that the different individuals involved in a dispute may have 'wildly different ideas of what it means in practice'.[172] But it is not necessarily the *meaning* that is important: after all, individuals may reasonably disagree on what the paramountcy principle, for example, requires (and, indeed, this happens in court when the principle is applied inconsistently). There is no consistent means of establishing how and whether the child's best interests and welfare have been considered above all the other factors in the decision. Dignity may remain ill- or undefined, but for the parents who do not wish for their child to suffer, the premise of considering dignity may prove a prudent step to take as far as reconciliation is concerned. To have dignity strewn aside because it is too 'malleable' with no genuine attempt having been made to shape it whatsoever is not only a missed opportunity in legal and bioethical study but a final kick in the teeth for the parents who are already faced with losing their child long before they may have imagined. The premise that decisions, however undesired by the parents, are made consistently and in line with a strong principle such as dignity would provide further explanation of why—and, crucially, *how*—these decisions have been reached.

171 K Gollop, 'Pippa Knight—Harm Without Awareness' *The Transparency Project* (14 January 2021), available at <www.transparencyproject.org.uk/pippa-knight-harm-without-awareness/>, last accessed 4 July 2021.

172 ibid.

Conclusion

Be it as a result of constitutional rights or the requirements of a legal principle, both England and Wales and Germany seek to place the welfare and interests of the child at the centre of the decision-making process. Yet there are subtle differences which, in and of themselves, may not produce judgments which differ between the two nations, but nonetheless may influence *how* those decisions are reached and the consistency of those decisions.

Both having signed and ratified the United Nations Convention on the Rights of the Child, there is a shared consensus on the necessity, goals, and purposes of children's rights laws. What has been discussed in the preceding chapters of this thesis has also displayed a general consensus (with only a few exceptions) on how parental rights and responsibilities are dealt with when it comes to making treatment decisions for children. Where the distinctions lie mainly, however, is in how each jurisdiction implements the UNCRC into its domestic practice and how this influences the approaches taken to the task of resolving disputes when the suitability of those parental decisions is called into question by HCPs. Germany is gradually moving towards constitutional implementation of the UNCRC whilst England and Wales retain the paramountcy principle to provide a safety net for children's rights.

Each of these approaches reflects the circumstances which brought them into existence. Best interests assessments for children in Germany incorporate the constitutional guarantee of human dignity, among other basic rights, borne of a desire never to repeat the horrors of the Nazi regime. In England and Wales, the paramountcy principle is the product of common law evolution and reflects the development in attitudes towards children and children's rights that shifted markedly throughout the 19th and 20th centuries. But, whilst their roots are shared,

their applications are not. Germany's constitutional frameworks mandate a more static and concrete application of legal principles. Under the *Grundgesetz*, human dignity is given significant importance, which translates in practice to dignity being an essential part of the best interests assessment and the foundation of the decision-making process. Under the proposed reforms to Article 6 *Grundgesetz*, children's best interests will receive explicit constitutional recognition, elevating their importance whilst retaining the same level of parental discretion that has enabled families to flourish as free from state intervention as possible.

The paramountcy principle in England and Wales, on the other hand, is more fluid. Despite originating in statute, its interpretation and application by the courts has allowed it to evolve as societal attitudes towards children have developed. In lacking the stasis of, eg, the German approach, the paramountcy principle is susceptible to an insidious departure from true paramountcy of the child's welfare. Consequently, the paramountcy principle in practice is viewed better as a justification than as a guide. Decisions can be taken which produce an outcome favourable to one party—oftentimes the HCPs—and which are then justified under the paramountcy principle. In Germany, such freedom is not possible. Dignity is not so susceptible to mis- or reinterpretation.

Steps should be taken within English law to engage closer with the principle of dignity. That is not to say that England and Wales should closely emulate the German model because that approach and the *Grundgesetz* are grounded uniquely in a history that Germany and England and Wales do not share, but lessons can be drawn from how interpretations of human dignity by the *Bundesverfassungsgericht* can inform the resolution of disputes between parents and HCPs. What is certain is that the opportunity to engage meaningfully with dignity in *Parfitt*, that was so sorely missed, must not be repeated. It may be that Macklin's argument, that discussing

dignity will not change the judgments reached, is correct. Dignity may already be incorporated into the paramountcy principle and may not require its own special considerations outside of this. But dignity in and of itself is not a 'useless concept'.[173] It may well be malleable, but it functions as a lens through which other rights and interests can be examined, particularly when they come into conflict with one another. A meaningful attempt to engage with and to shape this malleable concept should be made before it can be discounted legitimately and it is unlikely that, after having engaged with dignity, the decision will be taken to discount it.

173 Macklin (n 157).

Chapter V

Conclusion

On ne découvre pas de terre nouvelle sans consentir
à perdre de vue, d'abord et longtemps, tout rivage.
André Gide[1]

Dignity, parental responsibility, and best interests

The previous chapters have shown that, in line with general shifts in the European attitude, the child's best interests have come to be recognised in Germany and England and Wales as the central point of focus in making medical treatment decisions. What became evident through a comparison of the two jurisdictions is that English law lacks a strong basis in principle which would assist the courts in assessing the child's best interests when a decision cannot be reached between the parents and healthcare professionals. Whilst the paramountcy principle provides that the child's best interests shall take precedence, there is no principle which explains *how* this should be given effect. The result of this is inconsistency and uncertainty. On the other hand, the German law benefits from the fundamental rights set out in the *Grundgesetz* and from human dignity, which acts as the foundational organising principle of Germany's constitutional arrangements. Dignity functions as a lens through which the best interests assessment can be undertaken. It has enabled a delicate balance to be struck between protecting legal certainty and respecting the individual value of the child and the patient-centric, case-specific approach that the best interests test requires.

1 A Gide, *Les Faux-monnayeurs* (Nouvelle Revue Française, 1925).

This thesis set out to reconcile the significance of the child's best interests with the responsibilities of parents to serve those interests, even when they conflicted with their own individual views. The German conceptualisation, based upon the fundamental rights set out in the *Grundgesetz*, delineates the relationship between the child's rights and the parents' interests as symbiotic and interconnected, with the parents' rights and responsibilities acting in service of the child's rights. The English law model, based largely in the common law informed by the Children Act 1989, provides the flexibility for the child's best interests to be considered on an individual, case-by-case basis, but lacks the rigidity and principle found in the German approach to underpin the decisions taken. In many ways this is due to England and Wales lacking a supreme constitutional document such as the *Grundgesetz*. That is not to say that the English law position can only be remedied with an *ersatz Grundgesetz*. The comparative element of this thesis has brought to light the utility of the principle of human dignity, which may assist the function and understanding of the English law frameworks without requiring a comprehensive upheaval of its institutions and jurisprudence.

Whilst the principle of human dignity may aid assessments of children's best interests, the position of parents in decision-making under German law may assist our understanding of *how* those best interests may be served. Children's rights and best interests can be understood as the teleological root and ultimate purpose of parental rights. In that same regard, parental rights are better understood not as rights of power but as responsibilities of service, as *dienende Rechte*, designed to prioritise not only the child's rights but the child's best interests. Thus, there may be instances where the parents are required to set aside their own views and interests in making treatment decisions for their child, be it in the clinical setting or when the matter must be referred to the courts. Parental responsibility, therefore, is not a *passe-partout* for unfettered parental choice when the child is unable to choose for

themselves but, equally, it is not an absolute restriction on the parents' ability to decide. There is a balance to be struck, and when the matter reaches the courts, this balance should be struck in accordance with the principle of human dignity.

The parents' duty to promote the child's best interests

Be it parental power or *elterliche Gewalt*, the historical considerations in Chapters II and III showed how both evolved into the contemporary formulations of parental responsibility and *elterliche Sorge*. The once explicit and unrestricted power over the child was eroded. Instead, parental responsibilities became ones of service—of minding and of caring—to be exercised in pursuit of a benefit to the child. As such, parenting gained a dualistic quality in the law's eyes, requiring now a respect and service for the child whilst maintaining the independence and autonomy that each family relies on to establish itself. If societal perceptions of these seemingly fundamental concepts can be so flexible, so must be the law's response and regulation of them. Previously, the position in law was that the parents had an absolute right to choose for their child; nowadays their freedom to choose is restrained by the duties they owe to their child, who is recognised as an individual rights-holder.

In line with the requirement that parental responsibility serves the child, it can be better understood as existing not as an absolute right but as a conduit for the child's rights and 'a dwindling right which the courts will hesitate to enforce against the wishes of the child' [2] as the child matures. As this happens, the child gains experience and knowledge which enables them gradually to participate in hearings over their treatment and further issues surrounding their welfare.[3] Consequently, the parents' choices become decreasingly determinative, for their authority 'starts with a right of control and ends with little more than advice'.[4] The law appropriately

2 *Hewer v Bryant* [1969] 3 All ER 578 (Lord Denning MR). See also *R (on the application of Axon) v Secretary of State for Health & Anor* [2006] EWHC 37 (Admin); *Gillick v West Norfolk and Wisbech Health Authority* [1986] 1 AC 112.

3 This is one of the goals of the UNCRC under Article 12.

4 *Hewer* (n 2).

recognises that children have a right to participation [5] and to exercise their individual decision-making competence independent from the parents' views, even though they still have responsibility for their child.[6] But for those children who will never be capable of making their own independent decisions and whose matters must be resolved through the best interests assessment, the aforementioned lack of a strong basis in principle risks undermining that task. Again, the principle of human dignity may assist here by emphasising the significance of the individual child patient's value against the backdrop of a parental decision which is unable to be challenged by the child's own views.

5 In this sense, 'the law' refers to domestic law in England and Wales and Germany, but this position is reflected at the international level in the UNCRC, Article 12.

6 See, eg, *Gillick* which led to the concept of Gillick competence, whereby children who are not yet 16 years of age are able to consent to some medical treatment. Once the child reaches the age of 16, they are able to make decisions under s 8(1) Family Law Reform Act 1969.

The insufficiency of 'best interests'

A recurring theme throughout this thesis was that disputes can arise not simply because of a disagreement over the decision to be taken, but over the language used to describe that decision. The language of 'best interests' may lead judges to conclusions that are markedly different from those reached by the parents. This is not necessarily negative: indeed, some level of disagreement over the child's interests may be beneficial to the final decision. Yet, any benefits gained from the flexibility of best interests being imprecisely defined and patient-specific are beleaguered by the reality that the assessment is no more than a subjective evaluation couched in objective terms with no guidance or principle to constrain the decision taken. This has implications beyond legal practice. A lack of consistency may be emotionally challenging for parents who may feel as though their attempts in earnest to do what they believe to be best for their child are sub-optimal or perhaps even negligent. It risks alienating those who seek passionately, albeit misguidedly, to discharge their duties to their child because there is no coherent universal basis on which best interests are assessed.

A similar issue calls the paramountcy principle into question given that, in practice, it may not amount to anything more than the primary consideration principle under the UNCRC, which itself faces the same issue of imprecision and subjectivity. In the case-law, both the best interests assessment and the paramountcy principle are framed as issues of weak discretion: the judge is required to use their personal judgment to decide a child's treatment, and they are constrained to consider only factors relevant to the decision made.[7] In reality, the inverse is true and these decisions are questions of strong discretion. Judges make decisions with no

7 This is similar to the task of 'choosing the five best men' discussed in R Dworkin, *Taking Rights Seriously* (8th edn, Bloomsbury, 2018), p 141.

normative constraints on the means by which they reach that decision, which 'does not mean the official is free to decide without recourse to fairness, but only that [their] decision is not controlled by a standard'.[8] What it also means is that decisions are taken with discretion that is not as limited as the subsequent judgment claims it to be. This is not helped by the language that decisions are taken by the courts, for this feeds into the assumption that judgments are rendered on objective grounds by an infallible decider. Rather, the deciders—the judges—are not simply 'the court': they are people, and people are fallible. It is difficult to accept that there is any degree of objectivity in the decision-making when one considers the inflated importance given to the parents' views in *Raqeeb* compared to how other landmark cases have been decided. Claiming that the best interests assessment is an objective rather than subjective one surely requires an acknowledgement that *Raqeeb* was not decided compatibly with this standard.

Yet whilst some seek to discount dignity as a 'subjective, malleable concept',[9] the same seemingly does not appear to be the case for the best interests assessment and paramountcy principle. Therefore, those who seek to support the best interests approach to decision-making, which is inherently subjective, should not then seek to disregard human dignity as a lens to make those decisions because they believe it to be subjective and therefore worthless. In practice, with each side holding opposing views on an ill-defined matter, subjectivity is an inevitable concomitant of the decision-making process. Human dignity as the foundation of human rights may itself be relatively undefined but, as per the discussion in Chapter IV, may help to guide decisions by being employed as a lens through which the child's interests may be interpreted.

8 ibid, 33.

9 *Parfitt v Guy's and St Thomas' Children's NHS Foundation Trust & Anor* [2021] EWCA Civ 362, [50].

For as valuable as dignity may be to resolving disputes over medical treatment, the parents do, and should, continue to play an important role in the decision-making process. But questioning or doubting the infallibility of the parents in the decision-making process is *not* the same as rejecting the possibility that they can decide at all. As much as it would be unsustainable for the parents to have the ultimate decision-making authority, it would be unthinkable to exclude them from the process altogether unless they choose themselves not to participate. Equally, the extent of their participation should remain their choice: it may go only as far as their choosing not to participate further. But they must have the opportunity to voice their views of their child's best interests, for depriving the parents of that choice in the first instance may would risk inviting increasingly adversarial litigation down the line as they seek to reinsert themselves into the decision-making process. Were this to happen, the focus would again be shifted away from the child, who should instead take precedence. In the same vein, the significant harm test has been argued to be insufficient as a decision-making metric given that it is assessed by the minimal protection that human rights afford. The threshold that the decision need only avoid causing significant harm to the child is set too low and poses issues for balancing the rights and interests of the parents with those of the child.

Balancing these rights and interests is a delicate task and one that must be sensitive to the unique social arrangements which extend beyond the law. In that sense, the German model may be helpful to English law as it demonstrates how dignity as the foundation of the international human rights arrangement can be used to interpret and inform rights in the domestic setting. In that respect, this thesis proposes that the German model may be beneficial in enabling English law to more consistently discharge its obligations under the UDHR and ECHR. One way it can do this is by explicitly defining the purpose of the best interests assessment as being the protection of the rights contained within those international frameworks and the

promotion of the values of those rights documents, with dignity at the core. In that sense, the assessment is framed as promoting the essence of human rights and the dignity and value of the individual. Then, a re-definition of the paramountcy principle may use the *Grundgesetz* as a model for how dignity has been elevated to being the paramount concern in German law. In addition to the child's welfare, the principle may be of greater value if it promoted explicitly the child's rights and the value of the child as an individual legal person.

Whilst this may be beneficial to English law in resolving matters concerning children, the difficulty would nonetheless remain of what dignity means and to what extent it is helpful for resolving matters concerning adult patients. This thesis has identified a number of additional issues, the resolutions of which fall outside the scope of the thesis but will be addressed in the PhD thesis to follow.

Further research and doctoral study

Whilst this thesis sought to address the potential for engagement with the principle of human dignity in the determination of children's best interests, the implications for greater engagement with dignity more generally go beyond the scope of this thesis. This is because dignity, despite acting as a cornerstone of German law, has received relatively little attention in English law, often being regarded as inconsequential and of no use to the clinical or judicial process. But dignity has been condemned without trial: in those judgments where it has been declared 'unnecessary' or otherwise unhelpful, the reasons for this have been unsatisfactory. Even when it has been raised as an argument by legal representatives, the assumption has been that dignity is unhelpful until such point as it avails itself to be helpful, though there has been no indication as to when that might be. How is it that human dignity can be regarded as an 'inviolable', paramount consideration in Germany, but it can be dismissed as 'useless' and of no real utility in England and Wales? Something appears to be missing. But it is not merely a question of transplanting the principle from German law into English law. Human dignity in Germany is the product of, and designed to fit into, Germany's unique constitutional arrangements which respond to an equally unique national history. Accordingly, the English law response to dignity must correspond with England and Wales' own values and legal history.

Assessing the role to be played by dignity will be the purpose of the PhD thesis to follow. It will consider more broadly the issue of end-of-life decision-making and the difficulties of the best interests test by comparing this with the German approach of presuming the patient's will, using dignity as a comparator to assess which approach best serves the patient. It will discuss how the German position can inform a restructuring of English frameworks and will propose reforms to the

Official Solicitor's role in treatment hearings to better represent the patient. The thesis will argue that the principle of human dignity can facilitate a refocusing of the decision-making process onto the patient, who often becomes forgotten in the mêlée for the final decision-making authority. It will also build on recent developments in the case-law and in the international arena that have seen greater engagement with dignity as it becomes a more prevalent consideration in domestic and international jurisprudence. This will be based to some extent on the notion that, if English law is to accord with human rights, it must engage with the foundational principles of those rights, with dignity being at the heart of any such discussion. The PhD thesis will seek to establish how dignity could be better engaged with under English law and how a closer analysis of the German law position may inform and assist the courts in reaching these difficult decisions as consistently as possible.

Bibliography and Works Consulted

——, 'Life-support row parents bid to name Newcastle doctors' *BBC* (5 February 2021) <www.bbc.co.uk/news/uk-england-tyne-55945787>, last accessed 6 February 2021.

——, 'Tafida Raqeeb: "Law Should Be Revisited", Say Parents' *BBC* (5 October 2019) <www.bbc.co.uk/news/uk-england-london-49944602>, last accessed 19 October 2020.

——, 'The Law in Relation to Women' (1887) 128 *The Westminster Review* 702. <www.bundestag.de/resource/blob/821650/6e8135b171374754191ed6e161b45a83/WD-3-013-21-pdf-data.pdf>, last accessed 26 August 2021.

Abbott KH et al, 'Families looking back one year after discussion of withdrawal or withholding of life-sustaining support' (2001) 29 *Crit Care Med* 197.

Akandji-Kombe J-F, 'Les obligations positives en vertu de la Convention européenne des Droits de l'Homme' (Belgium, 2006), available at <https://rm.coe.int/168007ff61>, last accessed 20 June 2021.

Anderberg P, Leep M, Berglund AL et al, 'Preserving dignity in caring for older adults: a concept analysis' (2007) 59 *Journal of Advanced Nursing* 635.

Annas GJ & Grodin MA, *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation* (OUP, 1992)

Auckland C & Goold I, 'Parental rights, best interests and significant harms: who should have the final say over a child's medical care?' (2019) 78 *Cambridge Law Journal* 2, 287.

——, 'Resolving disagreement: a multi-jurisdictional comparative analysis of disputes about children's medical care' (2020) *Medical Law Review*.

Balzer P, Rippe KP, & Schaber P, *Menschenwürde vs. Würde der Kreatur. Begriffsbestimmung, Gentechnik, Ethikkommissionen* (Freiburg, Alber, 1998).

Barclay S, 'Recognizing and managing conflict between patients, parents and health professionals' (2016) 26 *Paediatrics and Child Health* 7, 314.

Barendt E, 'Is there a United Kingdom Constitution?' (1997) 17 *OJLS* 1.

Bartlett P, 'Litigation Friend or Foe? Representation of 'P' before the Court of Protection' (2016) 24 *Med LR* 3, 333.

Batty D, 'Catalogue of cruelty' *The Guardian* (London, 2003) <www.theguardian.com/society/2003/jan/27/childrensservices.childprotection>, last accessed 15 November 2020.

Bertram H, 'Money, time, and infrastructure as elements of a new German family policy' in Holthus B & Bertram H (eds), *Parental well-being: Satisfaction with work, family life, and family policy in German and Japan* (Iucidium Verlag, 2018).

Beyleveld D & Brownsword R, *Human Dignity in Bioethics and Biolaw* (OUP, 2001).

Binding K & Hoche A, *Die Freigabe der Vernichtung lebensunwerten Lebens* (Leipzig, Meiner Verlag, 1922).

Birchley G et al, ''Best interests' in paediatric intensive care: an empirical ethics study' (2017) 102 *Arch Dis Child* 930.

Birchley G, 'Deciding together? Best interests and shared decision-making in paediatric intensive care' (2014) 22 *Health Care Analysis* 203.

——, 'The harm threshold and parents' obligation to benefit their children' (2016) 42 *J Med Ethics* 2, 123.

Birnbacher D, 'Menschenwürde—abwägbar oder unabwägbar' in M Kettner (ed), *Biomedizin und Menschenwürde* (Frankfurt, Suhrkamp, 2004).

Bissell S, 'Overview and implementation of the UN Convention on the Rights of the Child' (2006) 25 *Lancet* 689.

Bissett-Johnson A, 'What Did States Really Agree To? Qualifications of Signatories to the United Nations Convention on the Rights of the Child' (1994) 2 *International Journal of Children's Rights* 4, 399.

Black PG, Dress AR, Derrington S, & Lantos JD, 'Can a patient designate his doctor as his proxy decision-maker?' (2013) 131 *Pediatrics* 986.

BMFSFJ, 'Gesetzentwurf der Bundesregierung—Entwurf eines Gesetzes zur Änderung des Grundgesetzes zur ausdrücklichen Verankerung der Kinderrechte' (19.01.2021), available at <www.bmfsfj.de/resource/blob/165208/189dccd485dd00054ae6ff287d19fcfe/gesetzentwurf-kinderrechte-grundgesetz-data.pdf>, last accessed 26 August 2021.

BMJV, 'Abschlussbericht der Bund-Länder-Arbeitsgruppe „Kinderrechte ins Grundgesetz"' (14.10.2019).

——, 'Referentenentwurf: Entwurf eines Gesetzes zur Änderung des Grundgesetzes zur ausdrücklichen Verankerung der Kinderrechte' (22.11.2019).

Bridgeman J, 'The Provision of Healthcare to Young and Dependent Children: The Principles, Concepts, and Utility of the Children Act 1989' (2017) 25 *Med LR* 363, 375.

Britz G, 'Das Grundrecht des Kindes auf staatliche Gewährleistung elterlicher Pflege und Erziehung—jüngere Rechtsprechung des Bundesverfassungsgerichts' (2014) 69 *Juristen Zeitung* 22, 1069.

Budzikiewicz H in *Jauernig, Bürgerliches Gesetzbuch* (17th edn, CH Beck, 2018) § 1591 Rn 1.

Bundesärztekammer, 'Präambel der Grundsätze der Bundesärztekammer zur ärztlichen Sterbebegleitung' (2004).

Bundesregierung, 'Children's rights to be enshrined in the Basic Law' (2021), available at <www.bundesregierung.de/breg-en/news/rights-of-child-in-basic-law-1841338>, last accessed 25 August 2021.

Carnevale FA, Canoe P, Cremer R et al, 'Parental involvement in treatment decisions regarding their critically ill child: A comparative study of France and Quebec' (2007) 8 *Pediatr Crit Care Med* 337.

Cave E & Nottingham E, 'Who knows best (interests)? The case of Charlie Gard' (2018) 26 *Med LR* 3, 189.

Choudhry S & Fenwick H, 'Taking the rights of parents and children seriously: Confronting the Welfare Principle under the Human Rights Act' (2005) 25 *OJLS* 3, 461.

Coester M in *Staudinger Kommentar zum Bürgerlichen Gesetzbuch, Buch 4, Familienrecht §§ 1638-1683 BGB* (13th edn, 2004).

CRAE, *Children's Rights in the Courts* (2012), available at <www.crae.org.uk/media/26279/childrens-rights-in-the-courts.pdf>, last accessed 25 August 2021.

Dassler S & Loy T, 'Drama um krebskrankes Kind an der Charité' *Der Tagesspiegel* (Berlin, 20.11.2012), available at <www.tagesspiegel.de/berlin/eltern-lehnen-beinamputation-ab-drama-um-krebskrankes-kind-an-der-charite/7413334.html>, last accessed 5 February 2021.

Davies D & Mack C, 'When parents say "more" and health care professionals say "enough"' (2015) 20 *Paediatr Child Health* 3, 135.

Dawkins R, *The God Delusion* (Houghton Mifflin, 2006).

De Schutter O, *International Human Rights Law* (2nd edn, CUP, 2017).

Dederer HG, 'Kinderrechte auf internationaler und supranationaler Ebene. Bestandsaufnahme und Ausblick' in Uhle A (ed), *Kinder im Recht. Kinderrechte im Spiegel der Kindesentwicklung* (2019).

Deutscher Bundestag, 'Entwurf eines Gesetzes zur Neuregelung des Rechts der elterlichen Sorge' (Drucksache 7/2060, 02.05.74).

——, 'Schlussbericht der Enquete-Kommission "Recht und Ethik der modernen Medizin"' (14/9020, 14.05.2002).

——, BT-Drs 8/2788.

——, *Definition des Begriffes Kindeswohl* (2021, BT-Drs. 19/23317).

——, *Entwurf eines Gesetzes zur Erleichterung familiengerichtlicher Maßnahmen bei Gefährdung des Kindeswohls* (Drucksache 550/07, 10.08.07).

Deutscher Ethikrat, *Selbstbestimmung und Fürsorge am Lebensende* (Berlin, 2006).

——, *Zur Regelung der Suizidbeihilfe in einer offenen Gesellschaft: Deutscher Ethikrat empfiehlt gesetzliche Stärkung der Suizidprävention* (2014).

DGMR, 'Empfehlungen zur Therapieverweigerung bei Kindern und Jugendlichen' (Medizinrechtlichen Aspekten der Therapieverweigerung bei Kindern und Jugendlichen, Einbeck, 1995).

Dorries A, 'Mixed feelings: physician's concerns about clinical ethics committees in Germany' (2003) 15 *HC Forum* 3, 245.

Dorsch G, *Die Konvention der Vereinten Nation über die Rechte des Kindes* (1994).

Douglas G, 'The Retreat from *Gillick*' (1992) 55 *MLR* 4, 569.

Duncker A, *Gleichheit und Ungleichheit in der Ehe: persönliche Stellung von Frau und Mann im Recht der ehelichen Lebensgemeinschaft 1700-1914* (Cologne, Böhlau Verlag GmbH, 2003).

Dürig G in Maurtz T, Dürig G et al (eds), *Grundgesetz - Kommentar* (9th edn, 1991).

Dworkin G, *The Theory and Practice of Autonomy* (CUP, 1988).

Dworkin R, *Taking Rights Seriously* (8th edn, Bloomsbury, 2018).

Dyer C, 'Parents fail to overturn ruling not to resuscitate baby' (2005) 330 *BMJ* 985.

Eekelaar J, 'Beyond the welfare principle' (2002) 14 *Child and Family Law Quarterly* 3, 237.

Eisenmenger W & Jox RJ, 'Pädiatrische Palliativmedizin: Die juristische Sicht' in Führer M, Duroux A, & Borasio GD (eds), *„Können Sie denn gar nichts mehr für mein Kind tun?" Therapiezieländerung und Palliativmedizin in der Pädiatrie* (Stuttgart, Kohlhammer, 2006).

Enders C, *Die Menschenwürde in der Verfassungsordnung. Zur Dogmatik des Art. 1 GG* (Tübingen, Mohr-Siebeck, 1997).

Evans MA (Eliot G), *Adam Bede* (London, John Blackwood, 1859).

Fateh-Moghadam B, 'Criminalizing male circumcision? Case Note: Landgericht Cologne, Judgment of 7 May 2012 – No. 151 Ns 169/11' (2012) 13 *German Law Journal* 9, 1131.

Feinberg J, *The Moral Limits of the Criminal Law: Harm to Others* (OUP, 1997).

Ferrere MR, 'The Inherent Jurisdiction and its Limits' (2013) 13 *Otago Law Review* 1, 133.

Fichte JG, 'Deduktion der Ehe' in Fichte JG (ed), *Grundlage des Naturrechts nach den Prinzipien der Wissenschaftslehre* (Leipzig, Christian Ernst Gabler, 1797).

Fortin J, 'International children's rights' in Fortin J (ed), *Children's rights and the developing law* (3rd edn, CUP, 2021).

Freeman M, 'Children's Rights as Human Rights' in Qvortrup J, Corsaro WA, & Honig M-S (eds), *The Palgrave Handbook of Childhood Studies* (London, Palgrave, 2009).

——, 'The Right to Responsible Parents' in Bridgeman J, Keating H, & Lind C (eds), *Responsibility, Law, and the Family* (Ashgate, 2008).

——, *The Rights and Wrongs of Children* (F Pinter, London, 1983).

Freeman MDA, 'Upholding the dignity and best interests of children: international law and the corporal punishment of children' (2010) 73 *Law and Contemporary Problems* 2, 211.

Freud A, *Kranke Kinder—ein psychoanalytischer Beitrag zu ihrem Verständnis* (Frankfurt, S Fischer Verlage, 1972).

Friedrichsdorf S et al, 'Status Quo of Palliative Care in Pediatric Oncology—A Nationwide Survey in Germany' (2004) 29 *Journal of Pain and Symptom Management* 2, 156.

Führer M et al, 'Entscheidungen am Lebensende in der Kinderpalliativmedizin: Fallberichte und ethisch-rechtliche Analysen' (2009) 157 *Monatsschrift Kinderheilkunde* 1, 18.

Führer M, 'Die Rolle des Arztes' in Führer M, Duroux A, & Borasio GD (eds), *„Können Sie denn gar nichts mehr für mein Kind tun?" Therapiezieländerung und Palliativmedizin in der Pädiatrie* (Stuttgart, Kohlhammer, 2006).

Gallagher A, 'What can we learn from the case of Charlie Gard? Perspectives from an inter-disciplinary panel discussion' (2017) 24 *Nursing Ethics* 7.

Gamlin R, 'An exploration of the meaning of dignity in palliative care' (1998) 5 *European Journal of Palliative Care* 187.

Geiger R, *Grundgesetz und Völkerrecht* (6th edn, CH Beck, Munich, 2013).

Gentleman A, 'Social policies in the noughties: 10 years of change and controversy' *The Guardian* (2009), available at **Error! Hyperlink reference not valid.**, last accessed 29 November 2020.

George R, 'The Legal Basis of the Court's Jurisdiction to Authorise Medical Treatment of Children' in Goold I, Herring J & Auckland C (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Oxford, Hart, 2019).

Gerhard U, 'Die Frau als Rechtsperson—oder: Wie verschieden sind die Geschlechter? Einblicke in die Jurisprudenz des 19. Jahrhunderts' in *Zeitschrift der Savigny-Stiftung für Rechtsgeschichte: Germanistiche Abteilung* (130th edn, 2013).

Gide A, *Les Faux-monnayeurs* (Nouvelle Revue Française, 1925).

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 *Clinical Ethics* 8, 3.

Gillon R, 'Why Charlie Gard's parents should have been the decision-makers about their son's best interests' (2018) 44 *J Med Ethics* 462.

Glendon MA, *The Transformation of Family Law: State, Law, and Family in the United States and Western Europe* (University of Chicago Press, 1989).

Goldstein J, 'Medical Care for the Child at Risk on State Supervision of Parental Autonomy' (1977) 86 *Yale Law Journal* 645, 650.

Gollop K, 'Pippa Knight—Harm Without Awareness' *The Transparency Project* (14 January 2021), available at <www.transparencyproject.org.uk/pippa-knight-harm-without-awareness/>, last accessed 4 July 2021.

Goold I, 'Evaluating 'Best Interests' as a Threshold for Judicial Intervention in Medical Decision-Making on Behalf of Children' in Goold I, Herring J & Auckland C (eds), *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (Oxford, Hart, 2019).

Griech-Polelle B, 'Image of a churchman-resister: Bishop von Galen, the euthanasia project and the sermons of summer 1941' (2001) 36 *Journal of Contemporary History* 1.

Grimm J, *Deutsche Rechtsaltertümer* (Reprint der 4. Aufl. 1899, Darmstadt, 1983).

Gröschner R, *Menschenwürde und Sepulkralkultur in der grundgesetzlichen Ordnung. Die kulturstaatlichen Grenzen der Privatisierung im Bestattungsrecht* (Boorberg, 1995).

Guo Q & Jacelon CS, 'An integrative review of dignity in end-of-life care' (2014) 28 *Palliative Medicine* 7, 931.

Hall M, 'The Vulnerability Jurisdiction: Equity, Parens Patriae, and the Inherent Jurisdiction of the Court' (2016) 2 *CJCCL* 1, 185.

Halliday J, '"Call from God": American pro-lifer's role in Alfie Evans battle' *The Guardian* (2018) <www.theguardian.com/uk-news/2018/apr/28/call-from-god-american-pro-lifers-role-in-alfie-evans-battle>, last accessed 28 October 2020.

Helft PR, Siegler M, & Lantos J, 'The rise and fall of the futility movement' (2000) 343 *New England J Med* 4, 293.

Herring J, 'The Human Rights Act and the Welfare Principle in family law—conflicting or complementary?' (1999) 11 *Child and Family Law Quarterly* 3, 223.

Heywood R, 'Parents and Medical Professionals: Conflict, Cooperation, and Best Interests' (2012) 20 *Med LR* 29.

Hoerster N, *Ethik des Embryonenschutzes. Ein rechtsphilosophischer Essay* (Stuttgart, Reclam, 2002).

Hofmann H, 'Die versprochene Menschenwürde' (1993) 118 *Archiv des öffentlichen Rechts* 3, 353.

Hoggett B, *Parents and Children: The Law of Parental Responsibility* (Sweet & Maxwell, 1993).

Hölscheidt S in Meyer J & Hölscheidt S (eds), *Charta der Grundrechte der Europäischen Union* (5th edn, Beck, 2019).

Holthöfer E, 'Die Geschlechtsvormundschaft. Ein Überblick von der Antike bis ins 19. Jahrhundert' in Gerhard U (ed), *Frauen in der Geschichte des Rechts: von der Frühen Neuzeit bis zur Gegenwart* (Munich, Beck, 1997).

Hurley R, 'How a fight for Charlie Gard became a fight against the state' (2017) 358 *BMJ* 3675.

Inwald D, 'The best interests test at the end of life on PICU: a plea for a family centred approach' (2008) 93 *Arch Dis Child* 248.

Jacelon CS, Connelly TW, Brown R et al, 'A concept analysis of dignity for older adults' (2004) 48 *Journal of Advanced Nursing* 76.

Jackson E, 'Expert Reaction to Tafida Raqeeb Ruling from High Court' *Science Media Centre* (2019) <www.sciencemediacentre.org/expert-reaction-to-tafida-raqeeb-ruling-from-high-court/>, last accessed 10 November 2020.

Jestaedt M, 'Artikel 6 II und III' in *Bonner Kommentar zum Grundgesetz* (131st edn, 2007).

Kant I, *Grundlegung zur Metaphysik der Sitten* (Berlin, JF Harknoch Verlag, 1785).

Karle M & Gathmann S, 'Hearing the voice of the child: The state of the art of child hearings in Germany. Results of a nationwide representative study in German courts' (2016) 54 *Family Court Review* 2, 167.

Kilkelly U & Liefaard T, 'Legal implementation of the UNCRC: lessons to be learned from the constitutional experience of South Africa' (2019) *De Jure Law Journal* 521.

Kilkelly U & Lundy L, 'Children's rights in action: using the UNCRC as an auditing tool' (2006) 331 *CFLQ* 32.

Kilkelly U, 'Best interests of the child: A gateway to children's rights?' in Macfarlane LAB & Sutherland E, *Implementing Article 3 of the UNCRC: Best Interests, Welfare and Well-Being* (1st edn, CUP, 2016).

——, *The Child and the European Convention on Human Rights* (2nd edn, Routledge, 2016).

Kirchhof G, 'Die Kinderrechte des Grundgesetzes. Sollte die Verfassung zugunsten von Kindern geändert werden?' (2018) *NJW* 2690, 2691.

Knoepffler N, *Menschenwürde in der Bioethik* (Heidelberg, Springer, 2004).

Kon AA, 'The "window of opportunity": Helping parents make the most difficult decision they will ever face using an informed non-dissent model' (2009) 9 *American Journal of Bioethics* 55.

König H, Kohlstruck M, & Wöll A (eds), *Vergangenheitsbewältigung am Ende des zwanzigsten Jahrhunderts* (Springer, 1998).

Kopelman LM, 'The best-interests standard as threshold, ideal, and standard of reasonableness' (1997) 22 *J Med Philos* 3, 271.

Krappmann L, 'Anspruch und Kerngehalte der Kinderrechtskonvention der Vereinten Nationen' in Bielefeldt H, Deile V, Hamm B, Hutter F-J, Kurtenbach S, & Tretter H (eds), *Jahrbuch Menschenrechte* (Böhlau Verlag, 2010).

Krason S, 'The Charlie Gard Case: A Coming Together of Current Troublesome Realities' (2018) 23 *Catholic Social Science Review* 367.

Kudlien F, *Ärzte im Nationalsozialismus* (Kiepenheuer & Witch, 1985).

Kuhlen M, 'Entscheidungen am Lebensende in der Kinderpalliativmedizin. Ein Erfahrungsbericht aus der klinischen Praxis' (2009) 34 *Historische Sozialforschung* 4, 130.

Kuhse H, 'The Case for Active Voluntary Euthanasia' (1986) 14 *Law, Medicine and Health Care* 3-4, 145.

Lifton RJ, *The Nazi Doctors: Medical Killing and the Psychology of Genocide* (New York, 2000).

Lowe N & Douglas G, *Bromley's Family Law* (11th edn, OUP, 2015).

Lundy L, Kilkelly U, & Byrne B, 'Incorporation of the United Nations Convention on the Rights of the Child in Law: A Comparative Review' (2013) 21 *International Journal of Children's Rights*, 442.

Macklin R, 'Dignity is a useless concept' (2003) 327 *BMJ* 1419.

Marguénaud J-P, *La Cour européenne des Droits de l'Homme* (Collection Connaissance du droit, Paris, 2nd edn, Dalloz, 2002).

Marrus MR, 'The Nuremberg Doctors Trial in Historical Context' (1999) 73 *Bulletin of the History of Medicine* 1, 106–123.

Marshall D, 'The Construction of Children as an Object of International Relations: The Declaration of Children's Rights and the Child Welfare Committee of the League of Nations 1900-1924' (1999) 7 *International Journal of Children's Rights* 2, 103.

McGing C, 'The Children's Referendum 2012' (2014) 29 *Irish Political Studies* 3, 471.

Mendick R, 'Charlie Gard is being held 'captive' by the NHS, complains the family's spokesperson' *The Telegraph* (2017) <www.telegraph.co.uk/news/2017/07/12/charlie-gard-held-captive-nhs-complains-familys-spokesman/>, last accessed 30 November 2020.

Mezzofiore G, 'So Ashya's parents were RIGHT: Proton beam cancer therapy that forced family to go on the run to Spain because they couldn't get it on the NHS is as good as chemotherapy—and has fewer side effects' *Daily Mail Online* (2016) <www.dailymail.co.uk/news/article-3424058/So-Ashya-s-parents-RIGHT-Proton-beam-cancer-therapy-forced-family-run-Spain-couldn-t-NHS-good-chemotherapy-fewer-effects.html>, last accessed 2 November 2020.

Mill JS, *On Liberty* (first published 1859, New York, Dover Publications, 2002).

Mnookin R, 'Child—Custody Adjudication: Judicial Functions in the Face of Indeterminacy' (1975) 39 *Law and Contemporary Problems* 3, 226.

Moore J & Kordick M, 'Sources of Conflict Between Families and Health Care Professionals' (2006) 23 *J Paediatric Oncology Nursing* 82.

Mowbray A, 'The European Convention on Human Rights' in Ssenyonjo M & Baderin MA, *International Human Rights Law: Six Decades after the UDHR and Beyond* (London, Routledge, 2010).

Münder J, Mutke B, & Schone R (eds), *Kindeswohl zwischen Jugendhilfe und Justiz* (1st edn, Juventa-Verlagt, 2000).

Murphy JC, 'Rules, Responsibility and Commitment to Children: The New Language of Morality in Family Law' (1999) 60 *University of Pittsburgh Law Review* 1128.

Nave-Herz R (ed), *Wandel und Kontinuität der Familie in der Bundesrepublik Deutschland* (Oldenburg, De Gruyter, 1988).

Nelson F, 'The agony of Alfie Evans' parents was made worse by bad law' *The Spectator* (2018) <www.spectator.co.uk/article/the-agony-of-alfie-evans-parents-was-made-worse-by-bad-law>, last accessed 29 October 2020.

Nida-Rümelin J, 'Wo die Menschenwürde beginnt' in *Ethische Essays* (Frankfurt, Suhrkamp, 2002).

Nipperdey HC, 'Die Würde des Menschen' in Neumann FL, Nipperdey HC & Scheuner U (eds), *Die Grundrechte* (2nd edn, 1954).

Order to Bouhler and Dr. [Karl] Brandt to increase the authority of physicians to perform euthanasia, Nuremberg document PS-630, dated 1 September 1939, available at <http://nuremberg.law.harvard.edu/documents/2493-order-to-bouhler-and-dr?q=evidence:%22PS-630%22#p.1>.

Orwell G, *Nineteen Eighty-Four* (Secker & Warburg, 1949).

Osman A, 'Conscience is Clear, Murder Case Doctor Says' *The Times* (3 April 1981).

Pais MS, 'The United Nations Convention on the Rights of the Child' (1992) 91 *Bulletin of Human Rights* 2, 75.

Platt H, *Platt Report: The welfare of children in hospital* (London, HMSO, 1959).

Podolski T, 'Stadt Wetzlar widersetzt sich dem BVerfG' *Legal Tribune Online* (26.03.2018) <www.lto.de/recht/hintergruende/h/bverfg-wetzlar-npd-versammlung-stadthalle-verbot-widersetzt/>.

Puppinck G, 'Affaire Charlie Gard : la limite du droit des parents au respect de la vie de leur enfant' *European Centre for Law & Justice* (2017) <https://eclj.org/euthanasia/echr/affaire-charlie-gard--la-limite-du-droit-des-parents-au-respect-de-la-vie-de-leur-enfant?lng=fr>, last accessed 5 November 2020.

Quinn B & Rawlinson K, 'Alfie Evans: police issue warning over online abuse of medical staff' *The Guardian* (2018) <www.theguardian.com/uk-news/2018/apr/25/alfie-evans-struggling-after-treatment-withdrawn-court-told>, last accessed 27 October 2020.

Quint PE, 'The Most Extraordinarily Powerful Court of Law the World Has Ever Known—Judicial Review in the United States and Germany' (2006) 65 *Maryland Law Review* 152, 153.

Ramnarayan P et al, 'Characteristics of deaths occurring in hospitalised children: changing trends' (2007) 33 *J Med Ethics* 255.

Reece H, 'The paramountcy principle: Consensus or construct?' (1996) 49 *Current Legal Problems* 1, 267.

Regilme SSF & Feijoo KV, 'Right to Human Dignity' in Romaniuk S, Marton P (eds), *The Palgrave Encyclopedia of Global Security Studies* (Palgrave Macmillan, 2021).

Reichel P, *Vergangenheitsbewältigung in Deutschland* (CH Beck, 2001).

Reuter D, *Kindesgrundrechte und elterliche Gewalt* (Berlin, 1968).

Riley S, 'The Function of Dignity' (2013) 5 *Amsterdam Law Forum* 2, 90.

Rossa E, *Kinderrechte: Das Übereinkommen über die Rechte des Kindes im internationalen und nationalen Kontext* (2013).

Roxin L, *Strafrecht Allgemeiner Teil. Grundlagen: Der Aufbau der Verbrechenslehre*, vol. 1 (5th edn, CH Beck, 2006).

Rutschmann P, 'Vergangenheitsbewältigung: Historikerstreit and the Notion of Continued Responsibility' (2011) 25 *New German Review: A Journal of Germanic Studies* 1.

Sabean DW, 'Allianzen und Listen: Geschlechtsvormundschaft im 18. und 19. Jahrhundert' in Gerhard U (ed), *Frauen in der Geschichte des Rechts: von der Frühen Neuzeit bis zur Gegenwart* (Munich, Beck, 1997).

Salzgeber J & Warning-Peltz S, 'Hearing the voice of the child: Current practice in family courts in Germany' (2019) 57 *Family Court Review* 3, 387.

Schicktanz S et al, 'The Cultural Context of End-of-Life Ethics: A Comparison of Germany and Israel' (2010) 19 *Cambridge Quarterly Healthcare Ethics* 381.

Schiemann G, 'Patria potestas' in Cancik H & Schneider H (eds), *Der neue Paly* (2000).

Schlink B, *Der Vorleser* (Diogenes, Zürich, 1995).

Schmahl S, 'Verpflichtet das Völkerrecht zur Einführung von Kinderrechten ins Grundgesetz?' (2020) *Recht der Jugend und des Bildungswesens* 1, 11.

——, *Kinderrechtskonvention mit Zusatzprotokollen* (Handkommentar, 2nd edn, Nomos, Baden-Baden, 2017).

Schmid H & Meysen T, 'Was ist unter Kindeswohlgefährdung zu verstehen?' in Kindler H & Lillig S, et al (eds), *Handbuch Kindeswohlgefährdung nach § 1666 BGB und Allgemeiner Sozialer Dienst (ASD)* (Munich, Deutsches Jugendinstitut eV, 2006).

Schmuhl HW, 'Nationalsozialismus als Argument im aktuellen Medizinethik-Diskurs. Eine Zwischenbilanz' in Frewer A & Eickhoff C (eds), *Euthanasie und die aktuelle Sterbehilfe-Debatte. Die historischen Hintergründe medizinischer Ethik* (Frankfurt-am-Main, 2000).

Schwab D, 'Familienrecht' in Willoweit D (ed), *Rechtswissenschaft und Rechtsliteratur im 20. Jahrhundert* (CH Beck, 2007).

Scott M, 'No, we don't need an Alfie's law' (Barrister Blog, 2018) <https://barristerblogger.com/2018/04/30/no-we-dont-need-an-alfies-law/>, last accessed 21 October 2020.

Scott PD, 'The Tragedy of Maria Colwell' (1975) 15 *British Journal of J Criminology* 88.

Seehofer H, 'Modellprojekt "Schizophreniebehandlung in der Familie"' (Baden-Baden, Modellverbund Psychiatrie, 1993).

Sengelmann H, *Der Zugang des einzelnen zum Staat* (Hamburg, 1965).

Sereny G, *Into that Darkness: An Examination of Conscience* (New York, 1983), p 48.

Shaw F, 42 *Hansard* 1053 (May 9, 1838).

Silverstein S, 'Voice' in *Falling Up* (Harper Collins, 2015).

Smith R, 'The ethics of ignorance' (1992) 18 *J Med Ethics* 117.

Sprecher F, *Medizinische Forschung mit Kindern und Jugendlichen nach schweizerischem, deutschem, europäischem und internationalem Recht* (Heidelberg, Springer-Verlag, 2007).

Statistisches Bundesamt (Destatis), 'Deaths: Germany, years, sex, age years' (2021), available at <https://www-genesis.destatis.de/genesis/online?sequenz=tabelleErgebnis&selectionname=12613-0003&zeitscheiben=5&language=en#abreadcrumb>, last accessed 16 November 2021.

Stoelzel A, *Das Recht der väterlichen Gewalt in Preußen* (Berlin, Decker, 1874).

Strauß FJ in *Bayernkurier* (09.07.1977).

Street-Porter J, 'I know how Charlie Gard's parents feel—but their trauma shouldn't be exploited for political gain' *The Independent* (2017) <www.independent.co.uk/voices/charlie-gard-gosh-great-ormond-street-hospital-ruling-pope-donald-trump-a7829351.html>, last accessed 31 October 2020.

Stroilov P, 'Lessons to learn from the story of Dr Abbasi's arrest' *Christian Concern* (13 August 2020), <https://christianconcern.com/comment/lessons-learnt-from-the-abbasi-case/>, last accessed 5 February 2021.

Tobin J, 'Article 3' in J Tobin (ed), *The UN Convention on the Rights of the Child* (2019).

Tomlinson D et al, 'Factors affecting treatment choices in paediatric palliative care: Comparing parents and health professionals (2011) 47 *European Journal of Cancer* 2182.

Tomlinson D et al, 'Factors affecting treatment choices in paediatric palliative care: Comparing parents and health professionals' (2011) 47 *European J Cancer* 2182.

Tushnet M, 'Weak-Form Judicial Review and "Core" Civil Liberties' (2006) 41 *Harv CR-CL L Rev* 1.

Uerpmann-Wittzack R, 'Die UN-Behindertenrechtskonvention in der Praxis des Ausschusses für die Rechte von Menschen mit Behinderungen' (2016) 54 *Abgabenverfahren und Rechtsschutz* 181, 211.

UN Committee on the Rights of the Child, 'Concluding Observations: Germany' (1995) CRC/C/15/Add.43.

——, 'General Comment No 13: The right of the child to freedom from all forms of violence' (2011) CRC/C/GC/13.

——, 'General Comment No 19: Public budgeting for the realisation of children's rights' (2016) CRC/C/GC/19.

——, 'General Comment No 5: General measures of implementation of the Convention on the Rights of the Child' (2003) CRC/GC/2003/5.

van Bueren G, 'Children's Rights' in Moeckli D, Shah S, Sivakumaran S, & Harris D (eds), *International Human Rights Law* (3rd edn, OUP, 2018).

van Leeuwen B, 'Free movement of life? The interaction between the best interests test and the right to freely receive services in Tafida Raqeeb' (2020) *Public Law* 3, 498.

Veerman P, *The Rights of the Child and the Changing Image of Childhood* (Dordrecht, Martinus Nijhoff, 1992).

Veit B in Bamberger G & Roth H (eds), *Kommentar zum Bürgerlichen Gesetzbuch* (3rd edn, Munich, 2003).

Vitzthum WG, 'Die Menschenwürde als Verfassungsbegriff' (1995) 40 *Juristen Zeitung* 5, 201.

von Gerber CFW, *System des Deutschen Privatrechts* (2nd edn, 1850).

von Goethe JW, 'Erfahrung und Leben' in *Einzelnheiten, Maximen und Reflexionen* (first published 1833, Bd 12, Hamburg, Christian Wegner Verlag, 1953).

von Landenberg-Roberg M, 'Symbolpolitik ohne Kollateralschäden?' *Verfassungsblog* (13 January 2021), available at <https://verfassungsblog.de/symbolpolitik-ohne-kollateralschaden/>, last accessed 26 August 2021.

von Salis LR, 'Beitrag zur Geschichte der väterlichen Gewalt nach altfranzösischem Recht' in *Zeitschrift der Savigny-Stiftung für Rechtsgeschichte. Germanistische Abtheilung* (7th vol, 1887).

Wapler F, 'Das Kindeswohl: individuelle Rechtsverwirklichung im sozialen Kontext. Rechtliche und rechtsethische Betrachtungen zu einem schwierigen Verhältnis' in Sutterlüty F & Flick S (eds), *Der Streit ums Kindeswohl* (1st edn, BELTZ, 2017).

——, 'Und ewig grüßt das Kindeswohl' *Verfassungsblog* (14 January 2021), available at <https://verfassungsblog.de/und-ewig-grust-das-kindeswohl/>, last accessed 26 August 2021.

Wapler F, *Umsetzung und Anwendung der Kinderrechtskonvention in Deutschland: Rechtsgutachten im Auftrag des Bundesministeriums für Familie, Senioren, Frauen, und Jugend* (Johannes Gutenberg-Universität Mainz, 2017).

WD, 'Aufnahme von Kinderrechten ins Grundgesetz: Fragen zum Gesetzentwurf der Bundesregierung' (01.02.2021), available at

——, 'Aufnahme von Kinderrechten ins Grundgesetz' (30.11.2017, WD 3-3000-226/17).

——, 'Kinderrechte im Grundgesetz—zur Grundrechtsträgerschaft von Kindern' (07.12.2017, WD 3-3000-242/17).

——, 'Sachstand, Kinderrechte ins Grundgesetz—Zum Gesetzesentwurf des Bundesministeriums der Justiz und für Verbraucherschutz' (23.01.2020, WD 3-3000-012/20).

——, 'Sachstand: Gesetzliche Regelungen der Elternshaft. Ein Überblick über Regelungen der Elternschaft und die Möglichkeit einer Mehrelternschaft in verschiedenen Rechtsordnungen' (WD 7 - 3000 - 146/18, 2018).

——, 'Zur Aufnahme von Kinderrechten in das Grundgesetz—Gegenüberstellung verschiedener Formulierungsvorschläge zur Verankerung von Kinderrechten in Art. 6 GG' (18.12.2019, WD 3-3000-272/19).

——, 'Zur Aufnahme von Kinderrechten ins Grundgesetz—Gegenüberstellung eines Formulierungsvorschlages mit vier kinderrechtlichen Grundprinzipien der UN-Kinderrechtskonvention' (16.12.2019, WD 3-3000-276/19).

Weiß K, *Lothar Kreyssig: Prophet der Versöhnung* (Gerlingen Bleicher, 1998).

Wellenhofer M in *Münchener Kommentar zum BGB (MüKo BGB)* (7th edn, CH Beck, 2017).

Wiesemann C, 'Von der Verantwortung, ein Kind zu bekommen. Eine Ethik der Elternschaft' (2006) 18 *Ethik Med* 213.

Wilkinson D & Savulescu J, 'After Charlie Gard: Ethically Ensuring Access to Innovative Treatment' (2017) 390 *Lancet* 540.

Willekens H, 'Die Geschichte des Familienrechts in Deutschland seit 1794. Eine Interpretation aus vergleichender Perspektive' in Meder S (ed), *Frauenrecht und Rechtsgeschichte: die Rechtskämpfe der deutschen Frauenbewegung* (Cologne, Böhlau Verlag GmbH, 2006).

Williams P, *The Alchemy of Race and Rights* (Cambridge MA, Harvard University Press, 1991).

Woolhead G, Calnan M, Dieppe P et al, 'Dignity in older age: what do older people in the United Kingdom think?' (2004) 33 *Age & Ageing* 165.

Wright D, '*De Manneville v De Manneville*: Rethinking the Birth of Custody Law under Patriarchy' (1999) 17 *Law and History Review* 2, 247.

Wyatt T, 'Rashid Abbasi: NHS doctor dragged from side of dying six-year-old daughter by police in shocking footage' *The Independent* (3 August 2020) <www.independent.co.uk/news/uk/home-news/rashid-abbasi-bodycam-footage-police-zainab-hospital-nhs-a9651326.html>, last accessed 6 February 2021.

Zacher H, '§ 134/Elternrecht' in Isensee J & Kirchhof P (eds), *Handbuch des Staatsrechts der Bundesrepublik Deutschland: Freiheitsrechte* (2nd edn, Heidelberg, 2001).

Zernikow B, *Palliativversorgung von Kindern, Jugendlichen und jungen Erwachsenen* (2nd edn, Berlin, Springer-Verlag, 2013).