Special Section: The Best Interests of a Child: Problematic Neuroethical Decisions

Minors and Contested Medical-Surgical Treatment

Where Are We with Best Interests?

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Abstract: Use of the best-interests test as the legal standard to justify medical treatment (or its cessation) in respect to legally incompetent adults or minors has come under sustained critique over the years. "Best interests" has variously been alleged to be indeterminate as well as susceptible to majoritarian ideology and inherent bias. It has also been alleged to be inferior to rights-based approaches. Against the background of several particularly hard cases involving minors discussed by Gillett in a prior article in this journal, this article considers some of these critiques. It concludes that these critical accounts make significant contributions to enabling a more procedurally and substantively robust consideration of what might be in a child's best interests. However, it is argued that none of these accounts alone provide a superior framework that would justify jettisoning the concept of best interests. Further, it is suggested that best interests still has an important role in achieving patient-centered decisionmaking in this context. It concludes by suggesting a taxonomy of considerations when determining best interests.

Keywords: minors; consent; medical treatment; best interests; rights

Introduction

Although guardians assume legal rights and responsibilities—including those regarding medical treatment—in relation to their minor children, parental authority is not absolute. While parents are generally presumed to be best placed to determine what is in their child's interests in the context of ordinary family life, the threshold for state intervention will be met if a guardian's decision regarding medical care will potentially cause significant harm to the child. Thus it is not uncommon for many Western jurisdictions to require court approval before, for example, a severely and permanently learning disabled minor may undergo certain elective, invasive, and irreversible procedures, such as hysterectomy for menstrual management or sterilization for contraceptive purposes. Similarly, in the case of minor conjoined twins when surgical separation poses significant risks or imperils the life of one of the twins, prior consideration by a court arguably should always be obtained.

In the context of less invasive but nevertheless contestable treatment regarding which a legally incapable child's guardians and clinicians agree, clinicians may seek an external, neutral opinion from a recognized ethical body before they proceed. Although an ethics committee's opinion does not have the same legal status as a court declaration regarding the lawfulness of a proposed treatment, it nevertheless affords an ostensibly informed, impartial, external appraisal of a proposed treatment regime that either endorses, or rejects, the proposal on

ethical grounds.² In contrast, a judicial decision pursuant to child welfare legislation is always, at least putatively, premised on the welfare or best interests of the child.³

In this context of medical treatment, the law is concerned with two questions. First, who has authority to make the relevant decision? If not the parents, the second inquiry concerns a substantive analysis of the normative criterion that determines the lawfulness of the proposed treatment: i.e. whether it is in the child's best interests. This article focuses on the latter issue: the credentials of the best interests test as the legal compass in the context of contested medical treatment.

However, given the emergent rights discourse that has been strengthened by international conventions such as the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), it is difficult to consider the notion of best interests without first locating it within a rights context. Consequently, the second section of this article considers the relevance of rights, and the third section examines the nature of rights and their relationship with the concept of best interests. The preliminary analysis of rights concludes that these concepts may, and should, be interdependent. Finally, the fourth section considers some of the critiques of best interests.

The Relevance of Rights

Although rights talk has become pervasive in the ethical and legal literature, judicial consideration of medical treatment in the case of minors, which is subject to child welfare legislation, is generally premised on the paramountcy of a child's welfare and best interests. However, there is often a perceived dichotomy between a best-interests approach and a rights-based approach, with best interests often being considered inferior to a rights approach. A recent example of this is provided by the Australian federal government's Report on Sterilisation of People with Disabilities.⁴ The report recommended that Australian states should adopt a best-protection-of-rights test in preference to a best-interests test.⁵ Similarly, in a comparative analysis of Canadian and UK decisions involving sterilization of learning-disabled adults for contraceptive purposes, legal academic Kristen Savell argued that two different narratives were apparent.⁶ The Canadian cases reflected that the right to bodily integrity was the dominant theme, whereas the UK cases employed a narrative of best interests.⁷

Implicit in accounts that promote a rights approach over best interests is an inherent dissatisfaction with the way in which the courts have conducted best-interests analyses. A common theme of these critiques is that best-interest accounts often fail to ascribe adequate respect for the individual's human dignity and rights. However, this article suggests that the apparent dichotomy between rights and best interests is not a necessary one. This is premised on two claims: first, that, based on Brennan's gradualist theory of rights (explained further subsequently), rights initially serve to protect a child's interests, rather than his or her choices, until he or she becomes legally competent to make his or her own decisions. If this is accepted, then it follows that best-interests analyses and rights analyses should not be mutually exclusive. Rather, rights-based reasoning should inform a best-interests analysis.

The Relationship between Rights and Best Interests

Many international instruments have enshrined human rights norms. The UNCRC accords a range of rights to minors, including the right to have their "best interests" be "a primary consideration" in all actions concerning them (Article 3). The term "primary" indicates, according to Archard, that best interests is "a leading consideration—one that is first in rank among several"; this can be contrasted with the term "paramount," which is often used in child welfare statutes. The UNCRC also reiterates a child's "inherent right to life" (Article 6) and the right of a child "who is capable of forming his or her own views . . . to express these views freely in all matters affecting the child" (Article 12).

The UNCRPD expresses additional relevant rights that specifically pertain to minors with disability. It reiterates the right to equality by decreeing that state parties "shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children" (Article 7.1); that "in all actions concerning children with disabilities, the best interests of the child shall be a primary consideration" (Article 7.2); and that every person with disability has "a right to respect for his or her physical and mental integrity on an equal basis with others" (Article 17).

Several points should be emphasized at this juncture. First, these conventions unequivocally establish that children, like adults, have claim rights in the sense that these rights correlate to the imposition of duties on others to do, or to refrain from doing, any act that would infringe that claim right. Further, although the conventions incorporate a best-interests approach, they also articulate additional claim rights, such as a child with disabilities' right to equal respect for his or her physical and mental integrity. Also significant is that although international human rights instruments must be specifically incorporated into a state's domestic law to be *legally* enforceable (as has occurred in the United Kingdom⁹) to the extent that these instruments articulate human rights norms, there is an obligation on ratifying states to interpret domestic laws consistently with them. ¹⁰ Having established the relevance of these instruments, the following addresses two preliminary issues: what rights seek to achieve and how rights function.

The Purpose and Function of Rights

According to one prominent rights theorist's account, rights in a liberal society ascribe certain interests *substantially* greater protection than other interests,¹¹ so rights claims have "special normative force." As Michael Freeman states: "To accord rights is to respect dignity: to deny rights is to cast doubt on humanity and on integrity. Rights affirm the Kantian principle that we are ends in ourselves and not means to others' ends." 13

Although the purpose of rights is relatively uncontroversial, there are different views as to how they function. Two conceptions of rights are the choice/will theory and the welfare/interest theory of rights. Choice theorists claim that rights serve to protect the autonomous choices of the rights holder. On this account, those incapable of making a choice would be precluded as rights holders. This approach is particularly problematic in the context of young children or those with severe cognitive impairment. In contrast, interest theorists claim that rights function to protect the *interests* of the rights holder and in so doing further the welfare or well-being of the individual.¹⁴

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The present analysis adopts Samantha Brennan's approach to determining the applicable rights approach, which is premised on the view that it is the nature of the rights-holding individual in any given case that determines whether rights will protect interests or choices. ¹⁵ Although Brennan formulates her argument in the context of moral rights, this can plausibly be extrapolated to interpreting the nature of rights declared in the international conventions under discussion, and this may inform a best-interests analysis. ¹⁶

A Gradualist Account of Rights

Brennan cogently argues that the model of rights providing the best fit in the context of minors is a gradualist one, such that the (theoretical) nature of a right is contingent on a child's status on the continuum of development that exists between childhood and early adulthood. Implicit in this approach is that the psychosocial process of development results in children changing from being the sort of beings "whose *interests* are protected by rights" to those "whose rights protect their *choices*." So whereas rights initially protect a young child's *interests*, this changes as the child develops intellectually, emotionally, and morally, such that the nature of his or her rights evolves to protect the individual's *choices*.

Importantly on this approach, the interest theory of rights affords rights both to a very young child and to a severely cognitively impaired individual who lacks capacity. In the case of a child who will develop legal capacity as a mature minor or young adult, or in the case of a cognitively impaired individual who may have the capacity to make his or her own decisions with supported decision-making in the future, ¹⁸ rights will gradually become premised on the choice theory of rights and will thereafter protect his or her choices. Also significant is an implicit caveat about the gradualist approach, which is that the assignment of rights on the interest theory cannot be counter to the (immature) minor's interests. This is consistent with legal philosopher Joel Feinberg's approach to child rights.

Feinberg claimed that rights generally protect an individual's basic welfare interests (including health, bodily integrity, privacy, and the inherent interest in being protected from harm). He also claimed, as do others, that children have an interest in having certain future rights protected (metaphorically, held in trust) until they reach adulthood and can determine their own values and conception of a good life. Feinberg characterized this as a child's "right to an open future" the corollary of which is children's right not to have their future interests illegitimately diminished or thwarted by decisions of their guardians, or by adjudicators, or by the minors themselves. This is not just an abstract philosophical concept. Although not discussed in rights language, the concept of protecting a child's future interests in best-interests determinations is well known to the law, as is exemplified in a recent decision of the UK Court of Appeal in the case of *Re G*.²²

Best Interests Determinations

The Court of Appeal case concerned a parental dispute over schooling—consequently, it was not a matter of potential risk or harm to the children involved but a private dispute that nevertheless had to be determined by reference to the statutory principle that the welfare of the child must be the "paramount" consideration. ²³ In this

context, the UK courts have considered that "welfare" is synonymous with "wellbeing" and "best interests." 24

Re G involved three children whose parents were raised as Chassidic Jews. After the parents separated, one parent wanted the children to attend an ultraorthodox single-sex school, and the other a modern orthodox school. The decision would have implications not only for the children's schooling but more broadly for their rules for living, which would determine to a large degree the options open to them as adults. Judge Munby, who delivered the lead judgment, applied a holistic approach to child welfare, stating that it

extends to and embraces everything that relates to the child's development as a human being and to the child's present and future life as a human being. The judge must consider the child's welfare now, throughout the remainder of the child's minority and into and through adulthood....

How far into the future the judge must peer \dots will depend upon the context and the nature of the issue. If the dispute is about whether the child should go on a school trip the judge will be concerned primarily with the present rather than the future. If the question is whether a teenager should be sterilised the judge will have to think a very long way ahead indeed. 25

Judge Munby expressly noted that decisions regarding schooling generally fall within the scope of parental discretion. After posing the question as to what the task of the ordinary reasonable parent is, he posited three values of contemporary society that he considered should inform the parental project. First of these was that "we must recognize that equality of opportunity is a fundamental value of our society." The second was to "foster, encourage and facilitate aspiration." The third objective

must be to bring the child to adulthood in such a way that the child is best equipped both to decide what kind of life they want to lead—what kind of person they want to be—and to give effect so far as practical to their aspirations. Put shortly, our objective must be to maximize the child's opportunities in every sphere of life as they enter adulthood.²⁷

Consequently, he opined that when such decisions are devolved to the court as "judicial parent," "the judge must be cautious about approving a regime which may have the *effect of foreclosing or unduly limiting the child's ability* to make such decisions in the future."²⁸ Arguably there is considerable synergy between Brennan's and Feinberg's approach to rights, and the legal principles applied judicially when determining a minor's best interests.

As already noted, a child's *welfare interest* in being protected from harm not only imposes obligations on others, it also places limits on the sorts of self-regarding decisions a child might make. Consequently, an interest in avoiding harm would justify limiting a child's liberty to make potentially disastrous self-regarding choices, until he or she is fully capable of understanding the implications of a decision. Therefore, an interest theory approach implies a right to be protected from harm, including potential harm arising from one's own (incapacitous) decisions.

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In a prior article in this issue Gillett provides a contemporary example that illustrates such a gradualist approach: the case of children with gender dysphoria, which is when a child is born one sex but identifies with the opposite sex.²⁹ An emerging approach to gender dysphoria in prepubertal minors is to initiate a course of drug therapy (puberty blockers) in order to forestall puberty and the development of secondary sex characteristics.³⁰ This buys time for the young adult to develop psychosocially and form stable, long-term preferences, while at the same time avoiding the development of secondary sexual characteristics. The rationale for what is fast becoming the orthodox approach to gender dysphoria accords with Brennan's interest theory of rights and Feinberg's concept of the right to an open future. That is, due respect is accorded to the implications of gender dysphoria on a minor's psychological and emotional health. To this end, treatment is given that will diminish the physical and emotional distress associated with sexual development, but a decision to commence irreversible sex-changing surgery is delayed until the child or adolescent reaches sufficient maturity to make permanent and life-changing decisions. Clearly, Brennan's approach mirrors the common law approach to the legal right to autonomy of minors, whereby autonomy and legal capacity is gradually developed with maturity and is commensurate with the significance of the decision at hand.³¹ Significantly, a gradualist (or competency-based) approach to rights also appears in judgments of the European Court of Human Rights.32

This brief analysis suggests that rights and best interests are not, or are not necessarily, mutually exclusive in the case of minors and the severely cognitively impaired. Rather, rights signal important interests that mandate respect and protection in determining best interests. However, this only takes us so far, as an adequate defense of the best-interests standard must be cognizant of its major criticisms. The following section addresses the nature of these critiques, and whether they are necessarily fatal to best-interests reasoning.

Critiques of Best Interests

Best Interests: Smuggling Assumptions Based on Majoritarian Values

The concept of best interests has been subject to ongoing critique.³³ A recurrent criticism of the best-interests standard is that it is susceptible to being hijacked by the particular ideological views or values of the decisionmaker,³⁴ a particular risk in the context of physical and/or cognitive "difference," as in the examples found in Gillett's article.

The disability rights movement has identified significant and problematic assumptions regarding disability and impairment made by the nondisabled.³⁵ It claims that majoritarian assumptions about the lived experience of disability are erroneously informed by the medical model of disability, which construes disability as exclusively resulting from physical and mental impairment. In contrast, the social model claims that it is not impairment per se that disables an individual but, rather, society that inadequately provides for persons with disability. Although it is not possible to go into this debate in detail here, two aspects of the critique are particularly relevant in this context. First is the claim that the medical model is premised on a (discriminatory) normal-abnormal dichotomy.

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It is claimed that "the normality-abnormality construct is an inherent feature of the medical model of disability where disability is perceived as an aberration which needs to be removed, corrected or hidden." On this basis, the disability rights movement challenges any best-interests decisions based on an assumed imperative to normalize what is considered by the mainstream as "abnormal," or "transgressively embodied," or simply "other." An inherent bias toward normalizing difference that is based on contestable assumptions regarding the lived experience of "differently" constituted human beings should clearly be a concern for the law. However, this article suggests that this does not pose a fatal challenge if those assumptions are expressly identified and openly scrutinized—as they often are in the disability studies, ethics, and legal literature.

Assumptions regarding anomalous embodiment are rife in the context of the examples provided by Gillett—yet it is not hard to also find accounts that challenge them. For example, the assumption that being conjoined is always an unqualified harm is disputed in the literature.³⁸ Similarly, the "full" Ashley treatment (involving radical medical and surgical interventions) has also been denounced by many of the disability rights community for breaching Ashley's "inherent" right to dignity based on contestable assumptions.³⁹ Ouellette quotes one disability rights advocate who claims:

This is the denial of a child's basic right as a human being to be free from the unwarranted and unnecessary manipulation of [her] basic biological functions merely to satisfy the needs of a third party. . . . Children with severe developmental disabilities are, first and foremost, human beings. The manipulation of a child's physical development relegates those receiving such treatment to a less than human category.⁴⁰

It has also been claimed that the Ashley treatment was informed by erroneous assumptions regarding disability and womanhood. Malhotra and Neufeld, who consider the Ashley treatment from a feminist and critical disability perspective, argue that "[t]he double oppression of being both a woman and disabled places Ashley in a situation in which her inability to perform the 'natural' function of a woman, bearing and raising children, means that her body is managed or disciplined in a more invasive and permanent manner than most women experience."41 Ethicist George Dvorsky provided a startling example of such reasoning. He responded to criticisms of the Ashley treatment by famously stating on an ethics blog that "the estrogen treatment is not what is grotesque here. Rather, it is the prospect of having a full-grown and fertile woman endowed with the mind of a baby."42 Such a problematic claim (which he has since acknowledged himself) sends a message regarding "anomalous" embodiment that many in the disability rights community rightly take issue with. It implies a value judgment that the individual is flawed simply because she does not conform to normal female embodiment and function, rather than focusing on a robust assessment of the best interests of the individual as informed by a critical assessment of the relevant claim rights, evidence regarding her lived experience of disability, and open-future/ future-agent considerations.

Gillett suggests that a "principle of psychosomatic harmony" may assist when making best-interests determinations. Although this is an appealing concept, unless it is adequately interrogated in each particular case, it could also become a tool for smuggling in majoritarian ideas of normalcy. Arguably, close scrutiny of the

objective underlying such requests for treatment is crucial. If it cloaks a view that treatment is necessary to "normalize" a child's "transgressive" embodiment and thereby avoid her becoming a "girl/woman" or a "child in a woman's body," it is premised on discriminatory and offensive sentiment (although intervention could still be in that individual's best interests based on alternative reasoning). To the extent that any decision is solely informed by discriminatory reasoning, the intervention would, morally speaking, constitute an abuse of power. In contrast, if best-interests reasoning is based on a robust assessment of the actual child's welfare and experiential interests and is not negated by open-future/future-agent considerations, such as opportunities gained by the child reaching his or her full growth potential or retention of fertility, no rights or abuse-of-power issues should arise.

A second important aspect of the disability rights movement's manifesto challenges what it claims is the "disabling" effect of inadequate social support for those with disabilities and their families. Consequently, a related critique of the best-interests analysis is the risk of judicial deference to clinical opinions that are solely informed by the medical model of disability. Beverly Clough argues that "while procedural protection [under the UNCRPD] entails an assessment of the individual's best interests, it is not necessarily clear that this will be undertaken in a way which adequately scrutinises the way in which the social environment may be augmented to enable liberty, or that best interests assessments can give effect to the changes necessary to enable this."43 This is an extremely important political point, although it does not appear to have significant traction in the context of the Ashley treatment. In an article in this issue, Kerruish examines parental and carer narratives both in support of and against the Ashley treatment. It is clear that additional social support would not alter the perspectives of many parents who support the Ashley-type treatment. The parental motivations described—such as to be able to hold, or nurse, or manually lift their child—are not amenable to social interventions such as the provision of hoists for lifting. In fact, parents express a desire to avoid mechanical aids because they reduce the one-on-one human contact that they and, they believe, their child value.

However, a pertinent question is whether, if the family were provided with more than adequate social support, the procedure would still be considered to be the best outcome for the particular child. If yes, then claims that the parents seek the Ashley treatment due to society's failure to provide families with adequate support are simply not persuasive. However, given the future-agent focus of a best-interests analysis, a further important question is whether, if that individual were eventually cared for outside of the family in the future, the treatment could still plausibly be in that person's best interest, or whether it would result in reducing meaningful experiences and opportunities. These questions imply that each case—rather than receiving a one-size-fits-all approach—needs to be informed by relevant research on the experiential aspect of disability.⁴⁴

Best Interests and Indeterminacy

A further criticism of the best-interests standard is that it is inherently indeterminate. ⁴⁵ Kopelman notes this critique and questions

whether we can really know what is in people's best interests. The best-interests standard . . . seems to suppose we can always agree about what

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is best, consider all the options, calculate all their benefits and harms, and pick the alternative that maximizes benefits and minimizes harms. . . . This is not just a daunting task, but virtually impossible, especially when one contemplates the myriad possibilities of the indefinite future. 46

There is no denying that making best-interests determinations may be extremely difficult—nevertheless, decisions must be made. What is important is that the relevant issues are conscientiously traversed, so that any decision is based on first principles—such as equal respect, facilitating a life lived well, and not unduly limiting possible future opportunities (including simple experiential pleasures)—from the perspective of the person at the center of the decision.

Best Interests as Individualistic: Relational Critique

Another challenge made to the best-interests standard is that it is overly individualistic and fails to account for other relevant interests.⁴⁷ Relational theory in particular challenges an individualistic approach to assessing best interests.

Relational theorists counter what they consider is the abstract "dominant liberal individualist" conception of the self by claiming that an individual is "socially connected, interdependent, socially encumbered, emotional, relationally constructed, socially constituted, and embodied." Herring explains that a relational perspective challenges an individualistic best-interests account because it "imagines that we can consider the welfare/best interests of a CLC [child or person lacking capacity] in isolation from those in a caring relationship with her." He argues for a more nuanced, relationship-based approach to welfare and best interests, stating:

To see CLC's interests outside their relationship with their carers could be said to be artificial and as excluding much of what is of value to CLC. Similarly, to view the interests of the carer without accounting for the interests of the CLC is to exclude many important issues. Relationship-based welfare/best interests allows for a clear focus on the CLC's past, on-going and future relationships.⁵⁰

A relational account suggests that when determining best interests, an individual's lived experience and future prospects should include consideration of the views of the guardians/carers who are directly involved in that person's network of care. This particular argument is not a critique as such but, rather, an argument for extending the views and interests considered beyond those of the primary individual to those immediately connected to the individual at the heart of the decision. Although responding to this account in detail is beyond the scope of this article, what may be claimed is that the perspectives of relevant others should not be simply dismissed as mere self-interest. However, an important qualifier is that the weight ascribed to such views should be dependent on the "quality of the caring relationship" in order to ensure that the best interests determination ultimately remains a patient-centred one. 52

Conclusion

This article makes several claims in the context of minors and contested medical treatment. First, it claims that rights and best interests are not necessarily dichotomous

but should be symbiotic. This argument is premised on the gradualist approach to rights articulated by Samantha Brennan, whereby the nature of the rights holder in question determines whether rights should protect interests or choices. To the extent that the rights holder is unable to make his or her own choices, as in the case of young minors or the severely cognitively impaired, rights should protect his or her interests. If that is accepted, then it was argued that rights reasoning might helpfully inform, but will not supplant, a best-interests analysis in such cases. However, given the importance best-interests reasoning assumes on this account, the credentials of best interests as the appropriate legal standard were interrogated. It was suggested that, although critiques of best interests should be heeded to improve judicial use of the concept, it would be unwise to jettison the concept.⁵³

Clearly, claim rights such as those contained in the UNCRC or the UNCRPD signal the importance of the interest being promoted or protected. Arguably, a best-interests approach is concerned with the broader issue of what will make a particular person's life *go best*. On this account, best-interests and rights analyses should be coherent, and rights should not be elevated above best interests, otherwise we risk rights (such as the right to found a family or to bodily integrity) becoming a mere mantra. Arguably, rights are empty if a decision is based on an uncritical upholding of an abstract right made at the expense of a thorough consideration of how an individual experiences day-to-day life, and what might make his or her life go best.

However, this claim is subject to important qualifications. While justifying the use of best interests as the appropriate legal standard in the context of minors, various critiques have challenged ideological biases in decisionmaking or, alternatively, have suggested that we should reformulate best interests. These critiques signal that a deeper analysis of the concept of best interests is necessary. They also reinforce the idea that the process and the adequacy of our reasoning are vital factors in best-interest determinations.

This analysis recommends a taxonomy, or road, map for judicial reasoning. First, when determining best interests, a range of evidence—medical, familial, and social—should be adduced. There is an obligation when analyzing this evidence to identify and test any potential assumptions regarding the lived experience of the person whose best interests are being considered, ideally with reference to the relevant critical literature. Clearly, a court may need assistance in this regard, and where a decision is likely to impact public policy, courts should consider using amicus curiae briefs to facilitate decisionmaking.⁵⁴ Exploring relevant rights-based arguments is also vital, but rights reasoning must be interpreted in the context of informing the question as to what is in that person's best interests. Further, it is axiomatic that any analysis of best interests should be child centered and should be informed by open-future/future-agent considerations. Ultimately, demonstrating respect for the individual—which is, after all, the common value underlying rights and best-interests principles—will best be achieved when the process of decisionmaking is informed, self-critical, and substantively robust.

Notes

1. Assuming there is no prospect of sufficient improvement in cognitive function for the individual to be capable of consenting or refusing consent themself in the future. See *F v. West Berkshire HA* [1990] 2 AC 1 and *Re B (A Minor) (Wardship: Sterilisation)* [1988] 1 A.C. 199.

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- 2. For example, the Ashley treatment involves a spectrum of interventions. Whereas sterilization generally requires a declaration from the court, clinicians wishing to provide growth attenuation therapy in the form of estrogen treatment have consulted ethics committees rather than the courts. Ethics committee opinions regarding considered growth attenuation have differed both across and within nations. See Slowther A. Clinical ethics committee case 3: Should parents be able to request non-therapeutic treatment for their severely disabled child? Clinical Ethics 2008;3:109–12; Isaacs D, Tobin B, Slaytor E, Donaghue K, Munns C, Kilham H. Managing ethically questionable parental requests: Growth suppression and manipulation of puberty. Journal of Paediatrics and Child Health 2011;47:581–4; Chisholm D. Let's talk about Charley. North & South, New Zealand 2013 June:66.
- 3. See, for example, Re T (A Minor) (Medical Treatment) [1997] 1 WLR 242.
- 4. Community Affairs References Committee. *Involuntary or Coerced Sterilisation of People with Disabilities in Australia*. Canberra: Commonwealth of Australia; 2013.
- 5. See note 4, Community Affairs References Committee 2013, at 5.126.
- Savell K. Sex and the sacred: Sterilization and bodily integrity in English and Canadian law. McGill Law Journal 2004;49:1093–141.
- 7. See note 6, Savell 2004, at 1124.
- 8. Archard, DW. Children's rights. In: Zalta EN, ed. *The Stanford Encyclopedia of Philosophy;* 2014 Winter; Edward N. available at www.plato.stanford.edu/archives/win2014/entries/rights-children/ (last accessed 10 Oct 2015).
- 9. The Human Rights Act 1998, s 3 (UK) expressly incorporates the European Convention on Human Rights (ECHR) into UK's domestic law. UK courts are statutorily required, as far as it is possible, to interpret legislation "in a way which is compatible with the Convention." In the first case involving a child with severe disabilities, the European Court held that clinicians who refused to continue actively treating a boy after complications occurred following a surgical procedure, *despite* the wishes of the boy's mother and legal proxy, breached the boy's Article 8 rights (the right to private and family life) under the convention. It was held that, given the disagreement, the boy's best interests should have been resolved by the courts. *Glass v. United Kingdom* [2004] 1 FLR 1019. See also *A Local Authority v. A* [2010] EWHC 1549 (Fam) 1.
- 10. Tavita v. Minister of Immigration [1994] 2 NZLR 257 (NZCA).
- 11. See Meyerson D. Understanding Jurisprudence. Abingdon: Routledge-Cavendish; 2007, at 122.
- 12. Leif W. Rights. In: Zalta EN, ed. *The Stanford Encyclopedia of Philosophy;* 2011 Fall; available at http://plato.stanford.edu/archives/fall2011/entries/rights/ (last accessed 11 Oct 2015).
- 13. Freeman M. What's right with rights for children. International Journal of Law in Context 2006;2:89–98.
- 14. Brennan S. Children's choices or children's interests: Which do their rights protect? In: Archard D, Macleod C, eds. *The Moral and Political Status of Children*. Oxford: Oxford University Press; 2002, at 55.
- 15. See note 14, Brennan 2002, at 64.
- 16. Indeed, to the extent that that states have ratified these conventions but have not directly incorporated them into domestic law, it could be argued that they are more accurately described as moral, rather than legal, rights.
- 17. See note 14, Brennan 2002, at 54.
- Devi N. Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities. *Journal of Law, Medicine and Ethics* 2013;41:793–806.
- 19. Some of the interests that Feinberg includes within the category of welfare interests are (nonexhaustively) health and vigor, "the integrity and normal functioning of one's body, the absence of absorbing pain and suffering or grotesque disfigurement," emotional stability, and so on. See Feinberg J. Harm to Others: The Moral Limits of the Criminal Law. Oxford: Oxford University Press; 1984, at 37, 62.
- Noggle R. Special agents: Children's autonomy and parental authority. In: Archard D, Macleod C, eds. The Moral and Political Status of Children. Oxford: Oxford University Press; 2002, at 106.
- 21. Feinberg J. The child's right to an open future. In: Aiken W, LaFollette H, eds. *Whose Child?* Totowa: Littlefield and Adams; 1980 at 126.
- 22. Re G [2012] EWCA Civ 1233.
- 23. Children Act 1989, s 1.
- 24. See note 22, *Re G* 2012, at [26]: "'Welfare,' which in this context is synonymous with 'well-being' and 'interests.'" See also Lord Hailsham LC, in *In re B (A Minor) (Wardship: Sterilisation)* [1988] AC 199, at 202.
- 25. See note 22, Re G 2012, at [26].

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- 26. See note 22, Re G 2012, at [79].
- 27. See note 22, Re G 2012, at [80].
- 28. See note 22, Re G 2012, at [80] (emphasis added).
- See American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, 5th ed. Washington, DC; 2013.
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- 53. A paradigmatic example of the type of approach to best interests and rights analysis suggested in this article may be seen in a recent decision of the UK High Court pursuant to the Mental Capacity Act 2005 (UK). The case involved not a minor but, rather, a 36-year-old severely learning disabled man whose IQ was assessed at 40. See *NHS Trust v. DE* [2013] EWHC 2562.
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