Special Issue: Bodily Integrity and Autonomy in Paediatric Populations

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Respecting bodily integrity and autonomy in pediatric populations

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Abstract

Children are treated differently to adults in liberal societies with respect to their right to bodily integrity. A commonly given justification for treating them differently is that they supposedly lack the sort of autonomy that is normally attributed to neurotypical adults. As such children fall through the cracks when it comes to protecting their bodily integrity: they are viewed as less than fully autonomous persons in philosophical, medical, and legal settings. With this editorial, we analyse current treatments of the concept of the child's right to bodily integrity and how this relates to their (developing or future) autonomy on various conceptions.

Keywords

Children's rights, bodily integrity, bodily autonomy, consent

The right to bodily integrity is widely accepted as being among the most important rights an individual has, often placed second only to the right to life itself. In adults considered competent to give or withhold morally valid consent, the right is often understood to prohibit any bodily interference, even touching, that is non-consensual, irrespective of expected harms or benefits or the good or bad intentions of the would-be interferer. It is also seen as something a competent individual can waive by an act of consent: thus, if someone consents to a round of boxing, to sexual contact or to undergo surgery, the boxer, lover or surgeon does not infringe the person's right to bodily integrity by punching, caressing or cutting them open, respectively, whereas they would do so if the individual had not consented.

The role of consent in determining what counts as a rights infringement thus appears to be central, at least for individuals considered *autonomous* with respect to a proposed interference or intervention (which is, on some views, neither more nor less than their being capable of validly consenting to the same). Understandably, therefore, the right to bodily *autonomy* is sometimes invoked in such contexts, making the link between consent and autonomy explicit.

But the rights are not simply synonymous or interchangeable. Commonly, it is held that the right to bodily *autonomy* – basically, the right to do with, or have done to, one's own body whatever one chooses, so long as one is adequately informed about the likely implications, chooses voluntarily and does not infringe the rights of others – is held by all and only those individuals who are in fact autonomous with respect to the choice in question.

The right to bodily *integrity*, by contrast, while it is also held by autonomous individuals, is often said to be held as well by those who are *non-autonomous*, whether with respect to some particular choice or intervention, or in general (say, those who are in a coma). Importantly for our purposes, then, given the focus of this special issue, which is paediatric populations, the right to bodily integrity is widely thought to be held even by the youngest of children, including babies, who may not be autonomous in the way that most adults are assumed to be.[1]

But what does the child's right to bodily integrity consist of? Under what conditions, and by virtue of what, is it infringed or violated? Insofar as a child is deemed incapable of either giving or withholding valid consent to an intervention,[a] it cannot be the case that the right is infringed by *any* non-consensual contact, as it arguably is for autonomous adults. Otherwise, this would imply that even necessary caretaking behaviour, such as nappy changing in the

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case of infants, would count as a rights infringement, which is absurd.

So, what then? If not non-consensual contact *per se*, what does it take to infringe a child's right to bodily integrity? Suppose we consider, for the moment, only those children who are, on any view, truly incapable of validly consenting to X. Further suppose that X involves 'any penetration into a bodily orifice, breaking of the skin, or alteration of a person's physical form' (p. 217).[2] Does X infringe on their right to bodily integrity just in case X is

(a) Medically unnecessary?
(b) Harmful?
(c) Very harmful?
(d) A serious encroachment into the body?
(e) Substantially contrary to the child's best interests, medically speaking?
(f) Substantially contrary to the child's best interests overall?
(g) Not what a reasonable person would consent to, if they were autonomous, under the circumstances?
(h) Not something we can be sufficiently sure the child themselves would consent to, if they were autonomous, under the circumstances?
(i) Something the child is likely to regret?
(j) Something it would be reasonable for the child to regret?
(k) Something that closes off certain important future options?

These are among the views that have been considered in the literature. All of them, however, point to a deeper question, namely: What is the *nature* of the child's right to bodily integrity? And how does this right, in turn, relate to the notion of autonomy when we are dealing with legal minors? Finally, when *do* children-as-minors have sufficient autonomy to make certain types of decisions – decisions, that is, that morally ought to be respected, even if others judge them to be unwise?

In addition to seeking to answer these theoretical questions, the authors whose work is featured in the current special issue offer various practical insights, drawing on examples ranging from the historical castration of young male singers to retain higher singing voices to the potential use of deep brain stimulation (DBS) to relieve symptoms of refractory obsessive compulsive disorder (OCD). Another major topic, explored in several papers, is the ongoing debate around medically unnecessary cutting or modification children's sexual anatomy, including female genital cutting, intersex surgeries[3] and newborn penile circumcision, with diverse perspectives included. Common to all the papers is a focus on the relationship between a person's bodily integrity and their autonomy, and what that relationship should mean when it comes to decisions to intervene in a young person's body.

Alderson,[4] citing earlier work by Daly,[5] argues that children's autonomy 'includes their self-determination, bodily integrity, and right to influence outcomes' and suggests that their autonomy, so conceived, should be 'promoted as a priority among children's best interests' (p. 3). Taking a strong position, she claims: 'All children's views should be respected unless there is significant risk of harm' (*ibid.*) This implies that children should, at least, be closely involved in the decision-making process around their own healthcare to the extent that is possible, with their preferences and attitudes given substantial weight. According to Alderson, this not only serves to respect and promote their developing autonomy but also increases the chances of positive treatment outcomes.

By contrast, Alderson suggests, there has been a long history of simply ignoring children's views or failing to take them seriously. And yet, even very young children show awareness of, and have meaningful preferences about, interactions with their bodies. Given this, Alderson argues that consent should be reconceived to include emotional and relational processes, and non-verbal responses, rather than treated as a transactional legal formality. The assumption that children cannot understand what is at stake in discussions about their care in medical (and other) settings, is, she argues, an example of epistemic injustice[6] whereby children are incorrectly assumed, within law, medicine and other fields, not to be genuine knowledge-holders in relation to their medical care. Thus, 'even when others signify consent for them, it is still vital to listen to children and young people and inform and involve them in decision making as much as they are willing and able to be involved' (Alderson,[4] pp. 4–5). She concludes that '[t]he riskier and more complex the decision, the more important this involvement may be, to respect children's bodily integrity and autonomy and best interests' (*ibid.*, p. 5).

Smith and colleagues[7] present the results of a series of interviews with child patients, caregivers and clinicians on the topic of DBS as a potential intervention for treatment-resistant OCD. The interviews aimed to gain insight into participants' views on who should make decisions about bodily interventions involving patients who are children; on who should have the final say in the decision-making process; and on what the role of respect for bodily integrity should be in identifying and evaluating child–patients' interests.

As they note, there are 'different conceptions of the right to bodily integrity that could inform whether specific actions constitute an impermissible infringement of this right' (p. 7). According to one view,[8] any 'serious' bodily intervention automatically infringes the right, but this can be justified if necessary to protect an even weightier right, such as the right to life. This would explain why life-saving emergency surgeries are generally considered permissible, or even obligatory, even though they may involve quite radical interference in a child's body while they are incapacitated or too young to consent.

An alternative view[9] holds that 'interventions may not even infringe upon [much less violate] the patient's bodily integrity if they are in the patient's best interest' (as summarised by Smith et al., p. 7). Applying these ideas to DBS, they write:

> On [the] first conception, DBS invades bodily integrity and infringes on that right because it requires the implantation of both a device and leads to deep brain regions and is thus a 'serious' bodily intervention in the strict sense, especially when compared to the current leading treatments for OCD: pharmacotherapy and cognitive behavioral therapy. On [the second] view of the right to bodily integrity, decisions made by a fiduciary (even those that are 'serious' bodily interventions) are not even infringements when they are in the pediatric patient's best interest, meaning in some cases DBS without patient assent would not infringe their rights. (*ibid.*)

Based on their interviews, Smith and colleagues found that '[p]atients and caregiver responses in our study align closer with the "serious encroachment" view than [the "best interests"] view given their general hesitancy to treat patients without their assent qua autonomous authorization' (*ibid.*). In this context, 'autonomous authorization' is given when "a patient or subject with (a) substantial understanding and (b) in substantial absence of control by others (c) intentionally (d) authorizes a professional" to perform some operation' (p. 278).[10]

This approach to informed consent, they note, centers the autonomous will of the individual, including the child patient, to authorise or give permission for – rather than merely comply with – some plan of action. By contrast, *effective consent* refers to a patient's valid authorisation as 'obtained through procedures that satisfy the rules and requirements defining a specific institutional practice in health care or in research' (p. 280).[10] This distinction allows Smith and colleagues 'to characterize situations where a patient may provide autonomous authorization for care even if they are unable to provide effective consent (e.g., due to laws governing age of consent). In such cases, typically the patient must... provide what is termed assent, in addition to caregiver or guardian consent for treatment' (p. 3).[7]

In other words, the interviewees in the study by Smith and colleagues expressed views that are consistent with Alderson's argument that minor children often do demonstrate sufficient autonomy for their views to be given substantial weight in making decisions about their medical care. Caregivers and potential patients emphasised the idea that the patient's body was theirs ('it's her body'), and as such, to respect children's right to bodily integrity it is necessary to have their willing permission: 'A recurring theme across the respondents was the consideration of the pediatric patient's right to bodily integrity as a reason to secure their assent and involve them in the decision-making process' (p. 5).

Following the contributions by Alderson and Smith and colleagues, three main papers have an explicitly theoretical focus and the authors strive to advance a substantive philosophical account of the child's right to bodily integrity. These are the pieces by Jonathan Pugh, Jospeh Mazor and Kate Goldie Townsend.

All three authors engage directly with the distinction between two main approaches to conceiving of rights: *will* or *choice* approaches, on the one hand, and *interests* approaches, on the other. They argue that children's rights theorists will generally need to take an *interests* approach to account for situations in which children do not have the autonomy required to justify a will-based approach. The authors also offer a response to arguments that use a *hypothetical consent* framework to understand the child's right to bodily integrity.[1,11,12] This approach takes a violation of bodily integrity to occur when one cannot be sufficiently certain that the child *would* consent to the intervention if they could (i.e., if they were sufficiently autonomous to do so), where the criterion for warranted certainty is set at or near the 'medically necessary' threshold, given that virtually any reasonable person would consent to such a procedure, suitably defined.[1,13]

Pugh[14] is one of the authors who objects to this hypothetical consent account. As he writes, 'In the case of individuals who have never had capacity (such as young children), it is not clear how we can apply a model of hypothetical consent; doing so requires us to hypothesise the values of a capacitous person who has not yet existed' (p. 4). Referring to the account of Brian D. Earp,[2] he notes that the latter 'recognises this difficulty and suggests in response that we should only presume consent for interventions that are almost universally regarded as promoting well-being' such as those that are medically necessary (p. 4). However, 'whilst this response avoids the conceptual difficulty of hypothesising the values of a person who has not yet existed, it appears that this presumed consent approach is no longer serving as an analogue of the patient's autonomy', which according to Pugh is why hypothetical consent accounts seem plausible when applied to temporarily incapacitated adults. Instead, he argues, 'it is an analogue for an objective conception of well-being grounded by universally valued goods and the goods of medicine' (*ibid.*). Problematically, however,

> such an objective standard of well-being may … provide only limited guidance in light of deep disagreements about well-being, even in the context of healthcare. Moreover, [a] standard grounded by universally agreed values will have trouble accommodating the possibility

> that future children might develop quite different values to those of currently existing generations. (*ibid.*)

To deal with this problem Pugh argues that 'rather than justifying infringement by hypothesising what the child would consent to [it] is more promising to incorporate considerations of autonomy into a beneficence-based framework [according to which] the strength of the child's claim against bodily interference is grounded, inter alia, by their interest in becoming an autonomous person' (*ibid.*). Thus, on his view, the conception of a child's right to bodily integrity must include the child's *development of autonomy* as an *interest* that should be protected and in many cases prioritised as a fundamental aspect of their right to bodily integrity. Pugh stresses the idea that embodiment is an essential dimension of a person's autonomy, as individuals use their bodies to engage with and in the world, and to develop, examine and express preferences.

On Pugh's account, autonomy is expressed or realised through the options a person has available to them, and if an important option is foreclosed in childhood through an intervention into their body that cannot be undone, then their sphere for exercising autonomy is narrowed.[15] As such, while it is impossible to protect or enable a 'fully open future' for children – as parents and carers always affect the sphere of options available, closing off some while leaving others open – it is important to properly consider the extent to which an intervention will impact on that child's autonomy-based interests throughout their life.

In a critique of Pugh's account, Mazor[16] challenges the idea that children's interest in *developing their capacity* for autonomy (DCA), as opposed to their interest in simply exercising their future bodily autonomy (i.e., their interest in deciding for themselves what should be done to their bodies in the future) has the significance it is given by Pugh. This is not to say that he disagrees with Pugh that children have a DCA interest, nor 'that this interest is important for human flourishing, and that it can be undermined by certain bodily interventions' (p. 8). Rather, he thinks that the kinds of bodily interventions that would actually violate this interest are already prohibited in liberal societies (e.g., lobotomising a child to treat her seizures, castrating a child to preserve his higher singing voice).

As he argues, 'very few physical interventions *currently debated in liberal democracies* have an effect on the DCA interest that is more than minor' (p. 9, emphasis added). Using the example of childhood male circumcision as a salient instance of this category, he suggests that the non-voluntary removal of the penile foreskin has only a relatively insignificant, 'circumscribed' effect on the child's choice set, where engagement with this choice set is understood as something that would be important for the development of an individual's capacity for autonomy. Mazor writes:

> Though the options this procedure closes off cannot be dismissed as trivial, it strikes me as implausible to characterise a man who was born without a foreskin as someone with substantially attenuated autonomy. If so, then it is difficult to argue that circumcision undermines the DCA interest merely because of the reduced options. The operation hardly threatens to narrow the child's options (sexual and otherwise) in a way akin to what was done to the castrati. (*ibid.*)

According to Mazor, 'in liberal democracies, people have ample opportunity to DCA in other ways, from the choice of career to the choice of life partners, to the choice of religion/philosophical belief. The idea that the millions of American men who have been circumcised have a significantly attenuated capacity for autonomous choice because they lack the ability to make this particular decision strikes me as far-fetched' (p. 10). Instead, Mazor prefers to think of the child's right to bodily integrity as being infringed only by interventions that are substantially contrary to the child's overall interests in expectation, where these interests include a child's DCA interest, their interest in future bodily autonomy (a kind of self-determination), and various other types of interests as well.

Townsend[17] offers a different account of the child's right to bodily integrity that emphasises the child's *welfare* interest in bodily integrity within a complex system in which an individual might have many competing interests. The welfare interest in bodily integrity, she claims, should always be prioritised above any *community*-based or *personal* ulterior interests. For Townsend, ulterior interests are personal if connected to an individual's preferences that they may develop against or independently of their cultural setting, or community based, if related to conformity with the norms and expectations of the setting. Townsend aims to address a schism in the debate about genital cutting or modification, whereby some authors prioritise children's interests which could be construed to include conformity to cultural or religious norms, or their capacity for autonomy, and those who emphasise the fact that children cannot – or the idea that it cannot reasonably be assumed that they would – give consent for genital cutting or modification.

Like Pugh, Townsend aims to combine considerations of interests and autonomy in her account of the child's right to bodily integrity, but instead of claiming that the right should prioritise the child's interest in developing autonomy,[14] she claims the right should prioritise the child's basic welfare interest in having their bodily integrity respected and protected, regardless of any interest they have in DCA.

The importance of this emphasis can be exemplified by imagining a child who we know will never become autonomous by commonly understood measures. On Townsend's view, this child is owed the same bodily protections as any other. Contrary to Mazor,[16] Townsend argues that the child's interest in bodily integrity should have moral priority over any interests they have in community-based phenomena such as conformity to religious practices, or normative expectations about the appearance of bodies. Townsend views community-based interests, such as those related to practices that signify religious affiliation (which Mazor views as essential interests), as *secondary* normative considerations. Townsend also reconceives Earp's concern about what the child would choose if they were autonomous as an ulterior interest, and thus of secondary normative importance.

Townsend suggests that community-based ulterior interests include norms about how bodies appear and function that are imposed on children with intersex traits, violation of whose rights is emphasised as a matter of urgency by Carpenter.[3] Carpenter's article 'Fixing bodies and shaping narratives: Epistemic injustice and the responses of medicine and bioethics to intersex human rights' was published in an earlier issue of the journal, but should be considered in concert with the present papers that focus on children's rights, how they are conceived, and in the case of intersex children, how they may be infringed by medical interventions that aim to make their bodies 'appear or function more typically male or female' (p. 3).

Carpenter argues that medical interventions aiming to 'fix' intersex children's bodies are sustained by a biomedical system characterised by epistemic injustice. For instance, within such an environment, there is non-disclosure of information about current medical practices, and discrediting of personal testimony of intersex communities and individuals. While Alderson, in her piece, explored how clinical practitioners are leading the way towards more just treatment of children by including them in decision-making, Carpenter views current medical approaches to treating intersex children, in particular, to be woefully unjust and exclusionary of intersex voices, arguing that change in medical practice is being led by intersex activists from outside of medicine. However, both Alderson and Carpenter view inclusion of the voices of the people affected as fundamental for enhancing their autonomy and creating more epistemically just medical spaces.

Fox and Thomson[18] trace several court cases involving children whose parents wanted them to undergo non-therapeutic penile circumcision for religious purposes and draw attention to arguments made in court that emphasise the parents' belief systems as the focus when weighing up the child's interests, rather than the child's bodily integrity. They argue that courts should instead centre the latter concept when assessing children's interests, where bodily integrity is understood to have both a 'negative' and a 'positive' aspect. The 'negative' aspect serves as a shield against unwanted intrusions: it is an interest in non-encroachment of the body due to its significance as the boundary of the individual. The 'positive' aspect they call 'embodied integrity', which refers to the active integration of the embodied self:

> This concept engages our lived experience of the body as the means by which we experience and become ourselves in the world. [It therefore supplements] the prevalent 'invasion narrative' that seeks to protect bodily boundaries, to acknowledge that our bodies enable us to pursue key dimensions of our humanity, such as our well-being, flourishing and our relationships, as well as the site at which we experience and enact our subjectivity.

As a consequence, they suggest, '[n]on-consensual and non-therapeutic embodied practices might therefore best be understood, not as one-off interventions, but as biographical. They potentially shape our life course and later embodied freedoms' (p. 2). In other words, if an individual's body is interfered with in ways that are unjust or that they do not autonomously select, then not only are their bodily boundaries interfered with but the shape and narrative of their life are affected.

Lempert[19] advances a related set of arguments but with a focus on how the embodied integrity of males and females is currently treated differently in UK ethical guidance on medically unnecessary genital cutting practices. In particular, Lempert flags contradictions in ethical guidance offered by the British Medical Association and the General Medical Council when it comes to Medically Unnecessary Penile Circumcision (MUPC). Lempert draws on the concept of 'medical necessity' to distinguish forms of the surgery that are necessary 'to prevent or resolve a serious threat to well-being due to a problematic medical condition' (p. 1), from those that are not, implying that the right to bodily integrity is infringed when interventions are performed that do not have the purpose of preventing or resolving such a threat.

Lempert argues that there are notable inconsistencies in the current treatment and social understanding of MUPC, particularly in relation to other types of medically unnecessary genital interventions. These inconsistencies, he claims, include the fact that medical guidance on genital cutting and modification of children differs depending on the sex category of the child, particularly when it comes to religious or cultural practices, where medically unnecessary female genital cutting practices are taken to be categorically impermissible when performed on minors who cannot consent, irrespective of expected harm or benefit, but MUPC is treated as permissible. Implicit in Lempert's critique then, is that the child's right to bodily integrity, *whatever* it consists of, must apply equally to all children irrespective of their sex characteristics or socially assigned gender, a view that has considerable plausibility.

Taking everything together, what have we learned about the nature of the child's right to bodily integrity? Some of the accounts in this special issue suggest that the right is infringed if the child cannot or does not consent and the intervention is *medically unnecessary.*[19] Others suggest that for the right to be plausible, it should include a commitment to protecting the child's interest in (developing their capacities for) autonomy, where the impermissibility of an intervention should be related to the extent to which it undermines the child's DCA,[14] or is not something one can be sufficiently certain the child *would* consent to if they were autonomous.[1]

Others downplay the role of autonomy in grounding the right, and instead focus on how it protects and promotes the child's interests. According to one of these interest-oriented views, the right is infringed if an intervention is sufficiently *harmful* or otherwise contrary to the child's interests with many contextual factors coming into play, such as the cultural or religious norms of the child's family.[9] While according to another, children's basic and fundamental *welfare interest* in bodily integrity should take conceptual priority over their potential, future or hypothetical *ulterior* interests, argued to be associated with an individual's preferences and life goals that they develop throughout their lives.[17]

The papers gathered here demonstrate that the question of the child's right to bodily integrity and how it can be conceived is far from losing its moral and practical urgency. Authors show us ways that the right is being applied and (according to some) violated in spaces purporting to promote the child's best interests; they illuminate many aspects of what is at stake when a child's body is subjected to an intervention in a medical setting. The papers each offer rich and compelling visions of the right to bodily integrity as a means to capture how children can best be protected and how their autonomy or capacities for autonomy might better be enabled when it comes to decisions about their own bodies and lives.

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Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

Note

a. A belief that may or may not be reasonable or justified, depending on the situation, unless one simply *defines* a child as one who is not yet developmentally capable of such consent, which is controversial.

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