

## **Embodied integrity, shaping surgeries, and the profoundly disabled child**

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### **Abstract:**

This chapter seeks to develop our model of 'embodied integrity' by addressing its capacity to protect profoundly disabled children from irreversible non-therapeutic bodily interventions and frame a more appropriate ethico-legal response to their care. Specifically, we suggest that the decision-making process in the controversial case of Ashley X. and much subsequent academic commentary, was impoverished and served to reify understandings of severely disabled children as frozen in a state of perpetual childhood and reducible to their bodies. In contrast, the conception of embodied integrity that we flesh out in this chapter takes account of these children's corporeality while also recognising that they are entangled in institutional and familial contexts. Responding to evidence of a growing demand for growth attenuation and shaping surgeries we argue that our embodied understanding of integrity promotes the immediate and future interests of children, including those who are profoundly disabled.

### **Key words:**

Embodiment, Bodily Integrity, Embodied Integrity, Disability, Children, Ashley X, Shaping surgeries, growth attenuation.

### **Introduction**

In this chapter we seek to develop a model of embodied integrity we have proposed elsewhere (Fox and Thomson 2017; Fox, Thomson and Warburton 2019) by applying it to the context of profoundly disabled children. We explore the role that embodied integrity might play in protecting such children from irreversible non-therapeutic bodily interventions. Bodily integrity is a key foundational value in the jurisprudence of the body and is increasingly understood as underpinning fundamental human rights (Brazier 2009). However, building on our earlier framework, we suggest that this value is not fully recognised in the lives of disabled people. Bringing together concerns with embodiment, care and disability, our more specific focus is on children such as Ashley X, whose condition was described by her parents as follows:

Our daughter Ashley had a normal birth, but her mental and motor faculties did not develop. Over the years, neurologists, geneticists, and other specialists conducted every known traditional and experimental test, but still could not determine a diagnosis or a cause. Doctor's call her condition "static encephalopathy of unknown etiology", which means an insult to the brain of unknown origin or cause, and one that will not

improve. Now nine years old, Ashley cannot keep her head up, roll or change her sleeping position, hold a toy, or sit up by herself, let alone walk or talk. She is tube fed and depends on her caregivers in every way. We call her our Pillow Angel since she is so sweet and stays right where we place her—usually on a pillow (<http://pillowangel.org>)

In responding to the question of how such severely disabled children can ‘have a life’ (Latimer 2019, 274) as they grow older and develop physically, we suggest that our embodied integrity model can help in framing an appropriate ethico-legal response to their care. Our vision builds on more conventional accounts of bodily integrity which, notwithstanding their increasing prominence in bioethics, socio-legal, and health law scholarship, were strikingly absent from much of the extensive academic and popular commentary that the Ashley X case generated. As we will demonstrate, although conventional accounts of bodily integrity may play a role in protecting children such as Ashley from interventions designed to manage their bodies, they are nevertheless problematic. In this context it is their tendency to treat the bodies of profoundly disabled children as fixed, asocial, and reducible to their material or corporeal bodies that is especially troubling.

Embodied integrity, by contrast, provides a more complex understanding of corporeality which acknowledges that the body is inseparable from the social and institutional context within which it exists. It is better equipped than conventional accounts to accommodate corporeal change and to situate these children as entangled (Latimer and López Gómez 2019) in the medical discourses and practices that surround them. Similarly they are intimately entangled in the lives of their families - a reality exacerbated by the privatisation of caring responsibilities. Paying to these social dimensions of bodies allows us to problematise surgical procedures on these children and to contextualise them in a long history of interventions on bodies constructed as improper or wrong (Sullivan 2008) - notably coercive sterilisation of disabled children and adults. Indeed, as Read and Clements remind us, only a generation ago it was ‘common practice to bring about the deaths of some children with learning disabilities or physical impairments’ (Read and Clements 2004, 482). Since then, although UK law has increasingly called the medical profession to account, as the sterilisation jurisprudence we outline below demonstrates, law continues to have a chequered record in protecting such disabled children and adults from invasive, irreversible procedures.

In contesting such interventions, recourse to the value of bodily integrity has become increasingly prevalent (e.g. Savell 2003-4), including in legal studies (Ludbrook 1995-6, Miller 2007, Brazier 2009, Grabham 2012, Ammaturo 2016, Fox and Thomson 2017, Herring and

Wall 2017). Bodily integrity has also generated an extensive ethics literature (Fabre 2007, Viens 2014, Mazor 2018). However, below we will argue that judicial decision-making, certainly in the UK, has yet to fully recognise the value of bodily integrity, reflecting the inconsistent way in which the bodily integrity principle is mobilised in law (Fox & Thomson 2017). Furthermore, notwithstanding what we might characterise as a *corporeal turn* in health law (Fox and Murphy 2103), when the language of bodily integrity is deployed it is often done with scant interrogation of how the concept is interpreted or how it might operate in practice. In this chapter our aim is to offer a more compelling justification for our embodied integrity model in medico-legal decision-making. We developed this model through a consideration of non-therapeutic interventions on the bodies of children who were not yet competent, but who were likely to acquire the capabilities to reason and choose that characterise the classical legal subject (Naffine 2003). Focusing on genital cutting, we argued that protecting the embodied integrity of children from non-therapeutic and non-consensual surgical interventions is essential to protecting their rights to self-determination and to an open future (Feinberg 2002). This requires that embodied integrity should be the primary factor in any assessment of the best interests of children by health decision-makers, and we argued that this will generally entail deferring decisions until the child is in a position to decide for herself about irreversible body modifications. In this chapter we seek to develop our model by applying it to the ‘harder’ case of managing the bodies of profoundly disabled children. Turning our attention to the particular body of children like Ashley X complicates our earlier reasoning by raising challenging questions about deferring decisions until a child is competent to decide, and how such competence is defined and recognised. While our focus is bodily interventions on children, it is important to acknowledge that they will grow to be disabled adults who, as we trace below using the jurisprudence on sterilisation, will likely continue to have decisions made for them and to have their bodily integrity disregarded.

As far as children are concerned, Read and Clements have traced how the formative legal cases which addressed withdrawal of treatment from disabled children (see further Bridgeman this volume) have generated other socio-legal challenges. A legacy of this jurisprudence has been that a greater number of families now live with disability, while ‘communities and municipalities hav[e] to cater for and accommodate disability’ (Read and Clements 2004, 484). One response to caring for these children in the home has been to medicalise their bodies by resort to surgery and other interventions designed to make the body more manageable. In this chapter we suggest that, too often, decision-makers have sanctioned such interventions on the assumption that these children lack any agency to contribute to decision-making about

their lives. We caution against assumptions that a profoundly disabled child will remain fixed in time (on the question of temporality in the legal construction of bodies see Garland and Travis, this volume) as well as a tendency to homogenise disability. We argue that our model of embodied integrity is broadly congruent with the social model of disability (Oliver 1996, 2013), or at least those variants that take into account the importance of corporeality (Hughes and Paterson 1997, Freund 2001, Shakespeare 2013, Barnes 2016). We also hope that it can have particular purchase in protecting the interests of the most marginalised legal subjects, and as underlining obligations to support decision-making by disabled people, as required by the UN Convention on the Rights of Persons with Disabilities (CRPD) (Flynn and Arstein-Kerlake, 2014; Harris 2016). Currently we see decision-making for profoundly disabled children as partly dictated by social responses to their (non-normative) corporeality and assumptions about their (lack of) agency. Often this centres on a ‘wrong body’ narrative which privileges medical management or normalisation (Sullivan 2008; Dietz 2018). Embodied integrity can contest such narratives by rendering visible the social meanings ascribed to bodily impairments and understanding the body as an emancipatory concept (Hughes and Paterson 1997). It also directs us, in line with approaches underpinning the CRPD, to seek to identify the ‘will and preference’ of the disabled child (or adult) and helps with the thorny issue of disentangling their interests from those of the families on whom they depend, thus problematising requests for non-consensual and irreversible interventions by family members.

We begin by outlining the case of Ashley X, the public responses it generated, and the subsequent afterlife of the ‘Ashley treatment’. Notwithstanding its international ramifications, the case failed to attract sustained legal analysis, while the ethics literature often relegated it to the status of a (sensationalised) one-off case study, in which bodily integrity received scant attention. We seek to contest the notion that such cases are exceptional, first by tracing media reports of global demand for this ‘treatment’ and then locating such practices in a genealogy of attempts to modify, contain, and render ‘non-reproductive’ the bodies of disabled children and adults (Trombley 1989). To contest these interventions we invoke the bodily integrity principle outlining how it is conventionally conceived before arguing that our embodied understanding better captures and promotes the immediate and future interests of children, including those who are profoundly disabled. We conclude by considering the role of law, and the need to challenge the privatisation of care that dramatically impacts those who care for disabled family members (Sakellariou, Rotarou 2017, 200). More generally, we argue for a legal conception of the child as emergent (Fox and Thomson 2017) and, following Read and Clements, for ‘the authenticity of impaired modes of being’ (Read and Clements 2004, 507).

To realise such ends we suggest that law must ‘avoid colluding with and adding to the power and dominance of an order of the normal’ (Mosel 2005, 668).

### **The Legacy of Ashley X**

In 2004 Seattle’s Children’s Hospital Ethics Committee considered an application by Ashley’s parents. Having consulted hospital doctors when she began to develop pubic hair and breast buds, they requested that high doses of oestrogen be administered to permanently stunt her growth, and that she undergo a hysterectomy and mastectomy. Her condition was described by her doctors as follows:

At the age of 6 years, she cannot sit up, ambulate, or use language. She is gastrostomy-tube dependent for nutrition... [S]he clearly responds to others – vocalizing and smiling in response to care and affection. The combined opinion of the specialists involved in her care is that there will be no significant future improvement in her cognitive or neurological baseline (Gunther and Diekema 2006, 1004).

The Committee approved the interventions in Ashley’s best interests to render her body more manageable, by allowing her to be more easily carried and cared for, thus facilitating her participation in family life (Diekema and Fost, 2010):

It was the consensus of the committee members that the potential long-term benefit to Ashley herself outweighed the risks; and that the procedures/interventions would improve her quality of life, facilitate home care, and avoid institutionalisation in the foreseeable future (p. 3, minutes).

Having justified these procedures within a cost-benefit framework, doctors also removed her appendix in the course of surgery, asserting that so doing presented no additional risk. In 2006 the doctors, at her parents request, published an account that attracted international media attention (Gunther and Diekema 2006).

Subsequently, the Washington Protection and Advocacy System (now Disability Rights Washington) concluded that the hospital had acted unlawfully by performing the hysterectomy without a court order, and that a court order *should* also be sought for a mastectomy or administration of growth attenuation (Carlson and Dorfman 2007). The hospital has not since

performed growth attenuation on a child with a developmental disability (Field 2016). Given the concerns generated by the case, the Seattle Growth Attenuation and Ethics Working Group was established to provide practical guidance for health professionals. Reporting in 2010, the twenty-person Working Group identified growth attenuation as the ‘particularly interesting’ intervention. It thus failed to consider the mastectomy (since to do so would only add ‘a layer of complexity’) and deemed it unnecessary to discuss the hysterectomy ‘because there is an established literature and a general consensus on policy, including the issue of judicial review’ (Wilford et al, 2010). Below we suggest that the failure to address the interventions as a suite of procedures was highly problematic, and allowed Ashley’s case to be read as exceptional and distinguishable from past interventions on disabled bodies that have increasingly been challenged for violating human rights. The Working Group ultimately concluded that growth attenuation could be a legitimate intervention for the most profoundly intellectually impaired children (defined as those with an IQ below 25).

Since the first account of Ashley’s treatment (Gunther and Diekema 2006), her case has attracted extensive international commentary, demonstrating a global uncertainty about the legitimacy of the practice (Vallis 2005, Ayres 2007, Cook 2007, Tanner 2007). The clinicians’ account generated reactions ranging from condemnation (Prigg 2007), through acquiescence (Lewis 2007), to approval (Singer 2007) from media outlets worldwide (Salaten 2007). Subsequently, the debate has resurfaced periodically across jurisdictions, as families have sought this ‘treatment’. Media reports are populated with these children’s pseudonyms, often accompanied by parental narratives of battles to care for their disabled children. For instance, in 2007 a mother in England sought a hysterectomy for her daughter, Katie (Boycott 2007). It was reported that if the ‘Ashley treatment’ had been available five years earlier, she would have pursued those interventions instead (Ainsworth 2007). Media reaction to this case was relatively positive (Anonymous Daily Telegraph 2007; Anonymous Brentwood Gazette 2007), although disability rights groups disputed the need for a hysterectomy (Smock 2007). The debate was reignited in 2012 (anonymous 2012) with news of Erica and Tom, the first boy recorded as having had aspects of the ‘Ashley treatment’ (McVeigh 2012). In 2015, having become aware of the treatment, the parents of Charley Hooper spent two years finding a doctor willing to perform it in New Zealand (Tsvirko 2015). The *New York Times Magazine* ran an extended feature in 2016 on 9 year-old Ricky Preslar who had been subjected to high levels of oestrogen from the age of 3 until his 7<sup>th</sup> birthday (Field 2016). In 2017 the Portland Tribune reported on Blue, who was given growth attenuation at the age of 9 after her mother publicised their desire for the procedure (Anonymous Portland Tribune 2017). While focused

on individual children, these various reports are typically accompanied by claims of a growing demand for the treatment.

The controversial nature of the Ashley treatment, coupled with the lack of transparency surrounding the activities of doctors, ethics committees, and hospitals means that it is unclear how many children, in any jurisdiction, have been subject to these interventions. Yet, the popular accounts above indicate that the publicity attracted by Ashley's case has generated a sizeable demand in the US, UK and elsewhere (e.g. Pilkington 2007, McVeigh, 2012, Field 2016, Wrigley et al 2018). In 2012 media reports suggested that at least twelve other instances of the treatment had occurred, with numbers potentially as high as one hundred globally (Pilkington 2012). Philip Zeitler, chair of the Endocrinology Department of Children's Hospital Colorado in Aurora, told *The Times* that since 2001 he had been approached on an annual basis by parents wishing to obtain growth attenuation treatment for their children (Pavia 2016) and was reported as having overseen growth attenuation in approximately 20 cases (Field 2016). A 2015 US survey of paediatric endocrinologists indicated that 65 children had undergone growth attenuation. Since only twenty-six percent of surveyed doctors responded, the number of actual interventions is likely to have been substantially higher (McGhee 2016). A 2016-17 study evidenced demand in New Zealand (Wrigley at al 2018), with five paediatricians having prescribed it and a further fifteen referring children elsewhere, including one to a clinician in the UK. More broadly, Curt Decker, director of the National Disability Rights Network (NDRN), suggested that thousands of families were actively exploring the possibility of the 'Ashley treatment' for their children (Bates 2012). Finally, in 2018 the blog established by Ashley's parents claimed that 'hundreds of children [had been] through growth attenuation therapy. Parents of about 50 of them are members of a private support group that we host' ([www.pillowangel.org](http://www.pillowangel.org)).

We argue that the precedent set by Ashley X in legitimising such interventions, coupled with the subsequent growth in interest and acceptance of ethical justifications (Edwards 2008, 343) raises significant concerns. These are heightened given that 4000 children (equivalent to 1 in 1000 births) are born each year in the US with the level of impairment that was deemed a threshold for intervention by the Working Group (Wilford et al 2010, 30). Hence a significant population of children are potentially subject to the same suite of procedures. Given that evidence suggests that the intellectual abilities of people with severe motor impairments are grossly under estimated (Serna, Dube, McIlvane 1997), it is essential that developmental specialists are involved in decision-making. However, it appears that this does not happen

(Field 2016), while the secrecy surrounding all aspects of the ‘Ashley treatment’ militates against accountability or compliance. Current uncertainty over the prevalence of the practice, combined with this lack of accountability, demonstrates a compelling need for empirical research into the demand for treatment, and responses by clinicians and ethics committees.

### **Fragmenting the person**

As noted above, the Seattle Ethics Committee decision and the Working Party were primarily concerned with growth attenuation. This partial focus is highly problematic given the overall attack on Ashley’s embodied integrity (Lantos 2010; Wrigley et al 2018). Yet, even within this narrow remit, the failure to consider the very contested history of growth attenuation is striking. Academic reports dating from the 1930s document emerging experimentation (Shimon and Barkan 2012, 193). The ability to isolate oestrogen (Lee and Howell 2006) offered the prospect of new treatment for children with acromegaly - a disorder resulting from excessive growth hormone once the growth plates have closed (Shiman and Barkan 2012) and gigantism (Lee and Howell 2006). However, oestrogen was soon more widely deployed to treat girls for ‘excess’ growth, rather than specific conditions. Indeed, to warrant growth attenuation, they needed only to have a predicted height of 5’9” (Goldzieher 1956) and during the twentieth-century it became a ‘standard treatment’ for tall girls (Lee and Howell 2006). This practice did not attract serious criticism within the medical community until the mid-1970s, when a gradual consensus emerged that it was overused (Marshall 1975). More recently, growth attenuation has been linked to breast and uterine cancer, and other common side effects have emerged, including leg cramps and headaches, with some patients developing migraines to the point of requiring the treatment to be halted (Rask et al 2008, 345). Nausea, weight gain, mild hypertension, benign breast disease and ovarian cysts have all been reported in growth attenuation treatments that took place through the 1960s-1970s. Additionally, they reduce antithrombin levels, leading to a hypercoagulable state and possibly decreasing Protein S levels (Rask et al 2008). These are risk factors for thrombosis and in fact Ricky Prezlar’s oestrogen treatment was stopped early when his toes turned blue, indicating thrombosis (Field 2016). While reports of its use continued (Lipsett 1977, Rask et al 2008), over time these documented risks, coupled with a greater social acceptability of tall women and absence of a clear ethical justification for the widespread use of growth attenuation contributed to a drastic decline in popularity (Barnard et al 2002, 25; Clark and Vasta 2006, 3). Against this backdrop of documented risks, we would suggest that the repurposing of growth attenuation to ‘treat’ profoundly disabled children is ethically and legally troubling. It becomes still more problematic

as one of a suite of invasive modifications, particularly since known side effects of the procedure are in turn used to justify performing mastectomies and hysterectomies (Field 2016).

Ashley's bilateral mastectomy, sanitised in some accounts as 'breast bud removal' (Frader 2007) or removal of 'breast nodules' (Field 2016), was initially omitted from Gunther and Diekema's report. Later they justified it due to the side effects of high-dose oestrogen, including 'heavy menstrual bleeding and rapid advancement of breast development' (Diekema and Fost 2010, 31). Complications of mastectomies include short term pain and swelling and normal surgical scarring. Seromas (fluid collecting under the skin) and Lymphoedema are further possible outcomes (NHS Choices 2017). Studies suggest that for 60 percent of mastectomy patients the short-term pain is 'severe', while 10 percent claim severe pain lasts for more than six months (Soubsey 2009, 76). Chronic pain is believed to last over a year in many patients (Gartner et al 2009, 1991). Still more problematically, mastectomies on these children have been justified for non-therapeutic reasons. For instance, Ashley's mother was not along in seeking the mastectomy to avert the risk of sexual abuse (Field 2016).

The other main procedure in Ashley's case was the hysterectomy which, in the narratives of parents who subsequently sought such treatment, was cast as central to the treatment. By discounting the hysterectomy her clinicians distinguished the Ashley intervention from a long and contested history of non-consensual modification of disabled bodies. Indeed, notwithstanding the power of discourses of reproductive autonomy and choice (Alghrani 2018) that are also at stake in sterilisation decisions, law's past ineffectiveness at constraining non-therapeutic sterilisation clearly demonstrates the fragility of reproductive and other rights in the lives of disabled people. Thus, as Lee and Morgan observed back in 1989, analysing the landmark House of Lords decision in *Re B*, 'the effect... (and perhaps the intention)' was 'to treat mentally handicapped [sic] young women in a manner quite distinct from other young women' (Lee and Morgan 1989, 134). Contesting Margaret Shone's controversial view that to refuse non therapeutic sterilisation of a disabled woman was 'to fragment the person' (Shone 1987, 639), Lee and Morgan asserted that '[o]n the contrary, to view the person as a whole, rather than atomised bits, mandates a wider view of what is at issue than simply reproductive organs'. Below we take up the potential of embodied integrity discourse to contest such fragmentation, but for now it is worth noting that just as growth attenuation fell into decline but was repurposed for this treatment, Ashley's sterilisation suggests that the issue of non-consensual sterilisation continues to be a legal and political concern.

As with mastectomies, hysterectomies - whether abdominal, vaginal or laparoscopic – carry side effects that must be balanced against intended benefits. Infectious complications following hysterectomy vary dependant on the procedure, but typically occur in 9-13 percent of all cases. Common infections include vaginal cuff cellulitis, infected haematoma or abscess, wound infection, urinary tract infection, postoperative haemorrhage, respiratory infection, and febrile morbidity (Clarke-Pearson and Geller 2013, 655). 25.9 percent of hysterectomy patients report at least one post-surgical complication in a two-year period after the surgery (Kjerulff et al 2000, 1445). As with growth attenuation, hysterectomies can lead to venous thromboembolic complications (Clarke-Pearson and Geller 2013, 659). They too cause significant levels of post-surgical pain, with chronic pain reported in 5 to 32 percent of all patients (Sobsey 2009, 97). Residual ovary syndrome, which is often very painful, is a common side effect of the type of hysterectomy utilised in the ‘Ashley treatment’, which causes the ovaries to enlarge (Rane and Ohizua 1998). For profoundly disabled children a key concern is their ability to communicate such pain and the impact of these complications on their quality of life. Significantly, these very concerns were raised to justify the appendectomy, an aspect of the interventions on Ashley’s body that has attracted no commentary in the ethics literature.

To demonstrate the inadequate attention paid in health law jurisprudence both to the complications of sterilisation and to the role of bodily integrity it is worth briefly revisiting the early sterilisation cases before the English courts. Aside from the first reported case of *Re D* in 1976, where Heilbron J refused an application to sterilise an 11-year-old girl because the procedure would involve ‘the deprivation of a basic human right, namely the right of a woman to reproduce,’<sup>1</sup> in rulings over the final quarter of the twentieth century judges eschewed any form of rights analysis (Lee 1987). This series of cases were read as pertaining to sex and pregnancy, with the twofold imperative of preventing pregnancy and restraining sexual behaviour of disabled adolescents and adults. Pregnancy was universally presented as a catastrophic outcome for a woman or girl with a mental disability or learning difficulties (Lee and Morgan 1987; Freeman 1987; Higginbotham 1989; Brazier 1990). As Lord Bridge opined in the leading case of *Re B (a Minor)* [1988] 1 AC 199, ‘It is clear beyond argument that for her pregnancy would be an unmitigated disaster. The *only question* is how she may best be protected against it’.<sup>2</sup> Judges were similarly preoccupied with containing sexuality, casting

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<sup>1</sup> Per Heilbron J, *Re D* [1976] 1 All E.R 326.

<sup>2</sup> At p205; our emphasis.

disabled people as either ‘out of control’ or ‘vulnerable to seduction’ (Savell 1990; Keywood, 1995). As Sandland notes, this fits with a general legal tendency to construct the sexuality of disabled people as monstrous (Sandland, 2013) rendering it easier to limit their rights. In contrast, over the same period, jurisdictions which placed a higher premium on bodily integrity reached different outcomes. In Canada, La Forest J in *Re Eve* highlighted the ‘grave intrusion on a person’s rights and the certain physical damage’ that would necessarily result.<sup>3</sup> Similarly, Brennan J in the leading Australian case followed *Re Eve* and explicitly couched the issue as one of bodily integrity rather than a right to reproduce, thus eschewing the possibility of trading this off against the interests of others: ‘the rule must give priority to the right to physical integrity and the human dignity it protected even though such a rule imposes burden[s]’.<sup>4</sup>

Decades later, UK judges have yet to exhibit such a clear commitment to protecting the disabled child’s bodily integrity. Certainly, as Kennedy and Grubb predicted, the higher profile accorded ‘rights talk’ following enactment of the Human Rights Act 1998 has prompted English courts to re-evaluate *Re B* and its progeny (Kennedy and Grubb 2000, 909), heralding an approach better attuned to the rights of incapacitated children and adults. In the sterilisation context this has entailed a more detailed cost-benefit framework for assessing best interests, which means weighing the:

advantages and disadvantages of the various treatment and management options, the viability of each such option and the likely effect each would have on the patient’s best interests and, I would add, his enjoyment of life...<sup>5</sup>

In such assessments case law has stressed that account must be taken of a broad range of factors which extend far beyond medical considerations.<sup>6</sup> Consequently, judges have demonstrated a willingness to explore less restrictive and invasive alternatives to sterilisation, which were notably absent from earlier decisions.<sup>7</sup> Moreover, since 2005 the Mental Capacity Act requires applications for non-consensual non-therapeutic sterilisation to be referred to the Court of Protection,<sup>8</sup> signalling their problematic nature. At the supranational level, the European Court of Human Rights (ECtHR) has been clear (albeit in a case concerning a

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<sup>3</sup> *Re Eve* [1986] 2 SCR 388 at 86

<sup>4</sup> *Department of Health and Community Services (NT) V JWB and SMB* (1992) 175 CLR 218, at 24

<sup>5</sup> per Dame Butler-Sloss in *Re A Hospital NHS Trust v S and Others* [2003] Lloyds Rep Med 137, at 47

<sup>6</sup> per Thorpe LJ in *Re S (Adult Patient) (Sterilisation: [2000]* 2 F.L.R. 389 at 560

<sup>7</sup> *Re S (Adult Patient: Sterilisation Patient’s Best Interests)* [2000] 2 F.L.R. 389

<sup>8</sup> Code of Practice 2007 para 8.18.

young woman found to be competent) that non-consensual sterilisation breaches various provisions of the European Convention on Human Rights (ECHR). Indeed, and notwithstanding the high threshold that needs to be satisfied for the Court to find a breach of the Article 3 prohibition on torture or inhuman and degrading treatment,<sup>9</sup> it ruled in a case involving Slovakia that sterilising a woman during a caesarean breached her Article 3 as well as Article 8 rights.<sup>10</sup> This ruling, as with the Australian and Canadian sterilisation cases, underlines the power of bodily integrity discourse. The absence of a similarly strong tradition in the UK means that protections are correspondingly weaker. The current approach is perhaps best summed up by the 2015 decision in *DD*, where Cobb J stipulated that:

Any proposal for significant, life-changing surgery, in respect of a person who lacks capacity will inevitably be (as it has been in this case) extremely carefully scrutinised, and only authorised where is clearly demonstrated to be necessary, proportionate and ‘best’ for the individual involved.<sup>11</sup>

Yet, ongoing paternalistic attitudes to those with disabilities<sup>12</sup> mean that such procedures are unlikely to be definitively ruled out in the UK. Thus, in *DD* the sterilisation was authorised, notwithstanding Cobb J’s acknowledgement that:

The ethical, legal and medical issues arising here self-evidently of the utmost gravity, engaging and profoundly impacting upon DD’s personal autonomy, privacy, bodily integrity, and reproductive rights (para 5).

He justified this outcome given DD’s obstetric history, which had resulted in six children being removed, medical evidence regarding the threat to life that a further Caesarean section would pose to her, and the strong likelihood that she would not comply with medical advice. Consequently the ‘predominant purpose’ of the sterilisation was to preserve DD’s life (at 130). It is noteworthy that, having considered an IUD/IUS as a less restrictive option, Cobb J invoked bodily integrity discourse to authorise the hysterectomy, since it would be a one-off procedure:

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<sup>9</sup> See, e.g. In the matter of an Application by the Northern Ireland Human Rights Commission for Judicial Review [2018] UKSC 27.

<sup>10</sup> Case of V.C. v Slovakia (Application No 18968/07)

<sup>11</sup> Re DD (No4) (Sterilisation) (2015) EWCOP 4

<sup>12</sup> A NHS Trust v DE [2013] EWHC 2562 (Fam).

[DD] has been consistent in maintaining a wish to be left alone, and to assert her personal autonomy in relation to her body... she is reported to have said that "if I cannot work my body and be who I am there is no point in being on this planet..." As her recent letter to Ms Y makes clear... "my body is mine", and she asserts "human rights" in relation to it. She abhors social work or other professional involvement in her life...

This case thus illustrates how deploying conventional bodily integrity discourse will not necessarily rule out non-consensual and irreversible surgical interventions.<sup>13</sup> Similarly, another recent decision, by Williams J, authorised a hysterectomy on 'Anne' – a young woman with autism, a severe learning disability, and endometriosis.<sup>14</sup> Other contraceptive options had been tried in her case, but expert evidence indicated that long term use of monthly injections of Decaenyl, as well as being distressing for Anne, carried an 'almost inevitable' risk of osteoporosis and other side effects. This led Williams J to concur with the Official Solicitor's view:

that this is significant life changing surgery which will impact profoundly upon Anne's personal autonomy, bodily integrity and reproductive rights. Nevertheless he supports the gynaecological intervention (and other interventions) as being in her best interests and thus lawful. They are necessary and proportionate interferences with her rights (at para 23).

As in the Ashley case, this intervention was cast as therapeutic (at para 35) and it was stressed that a key benefit was that 'likely improvements in Anne's behaviour as a result of not having to deal with her menstrual cycle or 3 monthly injections is likely to mean that her devoted parents will be able to care for her for longer than might be the case otherwise' (at para 40). Interestingly, similar objections had also been raised in Ashley's case about the likely distress that menstruation would occasion. Significantly, and again echoing Ashley's case, Anne's consultant psychiatrist testified that:

an effective intervention to minimise the monthly fluctuation in her mood and resolution of the abdominal pain she is experiencing will certainly make her behaviour more manageable and thus improve the quality of her life' (at para 22).

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<sup>13</sup> See also *A Local Authority v P (by her litigation friend, the Official Solicitor) The NHS Trust, A Family Member* [2018] EWCOP 10.

<sup>14</sup> *University Hospitals of Derby and Burton NHS Foundation Trust v J (by her litigation friend, the Official Solicitor) (Medical Treatment: Best Interests)* [2019] EWCOP 16.

William J's ruling illustrates well the continuities in how decision-making for profoundly disabled children carries over into their adult lives. It also evidences a preoccupation with menstruation which exemplifies Shildrick's contention that disabled people are defined 'as excessive, as contaminatory, as at once malign and helpless' (Shildrick 2005, 756). We explore in more detail below how these slippages between the interests of the disabled adult or child and their carers, and the rendering of disabled bodies as more 'manageable' are interpreted as improving the lives of children and adults. In authorising interventions an implicit notion of *family integrity* is mobilised to trump the bodily integrity of individual family members (Fox and Thomson 2017). For now, however, the key point is that, notwithstanding Cobb J's pronouncement that 'it will be a rare case... in which the more radical alternative of sterilisation will be found to be in the best interest of an incapacitous woman of child bearing age' (para 11), sterilisation continues to be sanctioned in several recent Court of Protection cases. This suggests that English courts have, at best, paid only lip service to the value of bodily integrity.

### **The Limits of Bodily Integrity**

In cases such as Ashley and Anne, as well as the broader jurisprudence on sterilisation and the limited discussions of growth attenuation, the body is clearly central (Savell 1990). And, as we noted above, legal scholars are increasingly turning to bodily integrity and asserting its psychological and jurisprudential primacy. Typically, such scholars rely on conventional understandings of bodily integrity, given the doctrine's powerful message to others to keep off our bodies. As Elizabeth Shaw contends, violating bodily integrity:

invades a particularly intimate sphere. The individual's body and mind are constitutive of the person and invading the mind and body therefore amounts to a fundamental attack on the person (Shaw, 2016, 9).

Thus, the right to bodily integrity as conventionally understood is a right to be free from physical interference. In Herring and Wall's words, 'it is the right not to have your body touched or your body interfered with without your consent' (Herring and Wall, 2017, 571). Similarly, in a landmark children's case, Walker L.J. defined it as 'the right to have one's own body whole and intact and (on reaching an age of understanding) to take decisions about one's own body' (per Walker LJ in *Re A (Conjoined Twins)* at 258). Law thus responds to the idea of sovereign control over the body by conceiving it as space which the individual is empowered to defend.

Consequently, Kristen Savell argues that an ‘invasion narrative’ underpins consent provisions preventing unwarranted medical interference with the body (Savell 2003, 1124). Such constructions of the body as bounded defensible space resonate with dominant understandings of the classical autonomous legal subject – what Ngaire Naffine terms the ‘man of law’ (Naffine 1998). Yet, while bodily integrity is thus inextricably linked with the right to make autonomous decisions, Herring and Wall argue persuasively that it is not reducible to autonomy, nor a mere subset of autonomy. In health law, bodily integrity comes into play when a patient refuses or withdraws consent to treatment and direct interference with the body is entailed (Herring and Wall 2017, 570). It is partly for this reason that Brazier deems bodily integrity to be ‘the core value’ in contemporary health law (Brazier 2009, 7). In its power to exclude others, it ‘literally and figuratively provide[s] the necessary walls’ to separate oneself from others (Herring and Wall 2017, 580). As Mary Koll has compellingly argued its value lies in protecting profoundly developmentally impaired children from unnecessary bodily invasion ‘even though self-determination is not possible’ (Koll, 2010, 240).

Conventional integrity then has many important benefits. For instance, its value in revealing harms that are otherwise downplayed can be traced in differential legal approaches to male and female genital cutting. Cutting of boys has traditionally been cast as a non-issue which is legally tolerated, whereas positioning female cutting as a breach of a woman’s bodily integrity has resulted in it being constituted as mutilation and regulated by criminal law (Fox and Thomson 2017). This is because to be justifiable infringements of bodily integrity require ‘the competing value to have considerable moral weight and practicable urgency’ (Herring and Wall 2017 583). As a result the most serious criminal offences constitute invasions of bodily integrity, and are cast as more serious than property and other offences which do not entail bodily invasion. Again, this can be seen in the genital cutting context, notably in the ruling by the Cologne District court that bodily integrity trumped benefits seen to derive from protection of cultural and religious traditions.<sup>15</sup> This case, like the law governing FGM, offers a powerful instance of the legal force of the invasion narrative, which in the case of children serves to limit parental powers to make irreversible decisions to modify their bodies. Conventional notions of integrity, therefore, have important revealing and protective effects, and had they been applied in the Ashley X case it would have been difficult for the ethics committee to have found as it did. Yet, although the ‘Ashley treatment’ seems a particularly clear violation of bodily integrity, this discourse and the considerable risks of the ‘treatment’ were consistently

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<sup>15</sup> Landgericht Koln (Cologne District Court), Judgment on May 7 (2012) No. 151 Ns 169/11.

absent from or downplayed in the ethics committee decision and subsequent commentary (with notable exceptions e.g. Koll 2010; Kittay 2011; Epstein & Rosenbaum 2019). As Alicia Ouellette remarks of the Committee which unanimously sanctioned the procedures in a sitting that lasted for a single hour:

[It] appears to have discounted entirely the physical harm the procedures would necessarily involve. It is as though the loss of a uterus, the removal of breasts, and the intentional disabling of normal growth had no significance or value. But these physical losses were in no way inconsequential. In any other context ... [it] would be considered abusive (Ouellette, 2010, 236.)

Clearly this resonates with other instances of how disabled people are subject to abuse under the guise of treatment.<sup>16</sup> Invoking bodily integrity doctrine would as a minimum have served to highlight such harms, and the significant risks of these experimental procedures documented above. Yet, even when commentators have acknowledged the principle, it has at times been summarily dismissed as inapplicable to disabled children. For instance, Steven Edwards concedes that:

'Ashley's "physical integrity" has plainly been violated. Her body has been radically changed, as has her future "trajectory" as a naturally developing being' (Edwards 2008, 342).

Yet, for him this objection 'does not seem compelling' since breaches of integrity may be legitimate. He invokes the analogy of an incompetent, severely physically disabled child trapped under rubble who requires a leg amputation to save her which he states would clearly be permissible, especially if the quality of the disabled person's life would be no worse than before. This logic is puzzling, but his analogy highlights a problematic strand of mainstream bioethics discourse. Such reasoning, dominated by individual ethical principles and technological developments, typically fails to attend to the social context of bodies and embodiment (Thomson 2018). In our context this failure is compounded by how children or adults with mental impairments are often afforded fewer rights and consideration than those with physical disabilities. Edwards' analogy problematically equates Ashley's healthy body with a physically disabled body that has undergone devastating injury and is in need of life-saving intervention. For as long as such hierarchies are maintained, both physically and

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<sup>16</sup> See e.g. *Hercegfalvy v Austria* (1992) 15 EHRR 437.

mentally impaired bodies will inevitably ‘fail’, or be rendered deficient in comparison to the idealised ‘normal’ or able body (Barnes 2016).

Thus, notwithstanding its potential power, conventional bodily integrity discourse has clear limitations. Moreover, as we saw in the case of *DD*, bodily integrity arguments can be invoked to *justify* sterilisation if alternative procedures also compromise bodily integrity. In consequence we argue that a richer formulation of integrity is necessary to overcome at least four problems with the conventional conception we have addressed previously. We have argued that conventional integrity defines the body as owned property thereby replicating a problematic mind/body split, that boundary metaphors associated with integrity exclude many forms of non-normative embodiment, that it opens up all bodies (but especially those of children) to excessive surveillance, and that it can mandate punitive responses which potentially criminalise the actions of caring parents (Fox and Thomson 2017, 517-8). Additionally, we have traced in this chapter how the ill-defined scope of bodily integrity allows it to be mobilised in partial, often contradictory, ways or even wholly neglected, as the deliberations of the ethics committee, the sterilisation caselaw and much bioethical commentary demonstrate. Furthermore, conventional approaches grounded in defending bodily boundaries remain ill-equipped to cope with anomalous or disabled embodiment, while the static nature of property-based conceptions of the body struggle to accommodate bodily change and development.

### **Towards Embodied Integrity**

Complementing the approach we develop in this chapter, Alan Hyde has highlighted the limitations of conventional integrity. While acknowledging its value, he suggests that what is needed is not a new or expanded right to bodily integrity, but rather:

... a bringing into consciousness of the multiple constructions already immanent in law, including alternatives to the body as property or privacy right or machine, alternatives that always treat people as embodied, that do not shy away from pain, sex or other embodied experiences, that replace the metaphors of property, machine or privacy right with a language of bodily presence... (Hyde 1997, 6).

In advocating a similarly embodied approach we build upon the turn within feminist and other critical theories from bodies to embodiment as the object and subject of analysis (Fletcher,

Fox and McCandless 2008; Thomson 2010). This shift addresses the limitations of the conventional body integrity approach, which as we have seen splits the body from the mind and conceives it as static, a feature which proves particularly problematic in freezing in time the body of the disabled child (see further Garland and Travis, this volume). Embodied approaches, in contrast, recognise the contingent, relational and biographical nature of bodies. They acknowledge that we experience our bodies in the context of discourses and institutional domains which shape our being in the world and mediate our relationship with it. Embodied understandings conceptualise bodies as more than instrumentally valuable, since they represent ‘a constitutive part of who we are’ (Kittay 2011, 617) and, importantly, who we may become. Thus, Chris Dietz has argued for embodiment to be understood as an ontological and epistemological process of becoming (Dietz 2018, see also Morland 2008). This feature, which contrasts with the static nature of conventional integrity approaches, renders embodiment an especially useful principle when medical interventions on children are proposed, since the child’s body is a ‘biologically and socially “unfinished” entity’ (Williams and Bendelow 1998, 20) in a constant state of emergence. Embodied integrity therefore accommodates the mutability, contingency, and plasticity of bodies (Fox and Thomson 2017, 519). Equally important, whilst conventional integrity is premised on the injunction to refrain from interfering with the bounded singular body, embodied integrity more readily encompasses a range of bodily states, including the ‘improper’ (Sullivan 2008, 112) bodies of disabled children. It ‘shift[s] attention from the singular body or even multiple bodies as objects of analysis by mandating a broader focus on lived experience and the question of how we inhabit and experience the world through our bodies’ (Fox & Murphy, 2013, 256). Like conventional integrity, the importance of being able to transcend our bodies, to take the body for granted in a way that can be denied when actions - violent or otherwise - compromise our physical being in the world, is acknowledged (Priaulx 2008). Indeed, for disabled subjects, as for other marginalised legal subjects, the prospect of forgetting one’s body and simply *being* embodied (Dietz 2018, 199) may be especially hard to achieve (Garland-Thomson 1997, Koll 2010). Moreover, in the context of the Ashley treatment, a focus on embodiment facilitates attempts to unpack the specificity of the threats to her integrity that this suite of interventions entails.

Our embodied integrity model is indebted to the theories of Joel Feinberg and Drucilla Cornell. Specifically, we have drawn on the potential of Cornell’s conception of bodily integrity (Cornell 1995, Ch 2) to substantiate and enrich Feinberg’s argument that children have a right to an open future (Fox and Thomson 2017). To recap briefly, Feinberg proposes that children have

autonomy rights that are held in trust for the adult that the child will become (Feinberg 2002). He argues that parents and others should refrain from actions that limit or deny options that the child should have when they reach adulthood. This resonates with Cornell's vision of bodily integrity, which casts it as an open-ended process that must be protected if a person is to be accorded equal citizenship. Guaranteeing bodily integrity creates a zone within which individuals may 'transform themselves into political citizens' (Cornell 2002, 431). Our model brings these strands of argument together in the claim that protecting a child's embodied integrity is necessary to realising an open future where she can make the embodied choices that are the hallmark of the sovereign person. Although infringements of bodily integrity can have the negative biographical implications that conventional integrity flags up, embodied integrity also engages more positive biographical dimensions of the body as a feature of future change and development, as well as a vehicle for self-expression. Embodied integrity therefore both protects the body from encroachment and secures the right to make future embodied choices, as our bodies develop and are impacted by their environment and other entanglements. As Grosz notes:

There is no bodily integrity in the sense of an unchanging continuity over time, only mixtures, ideas encountering each other and bodies affecting each other, each transforming and being transformed by its engagement (Grosz 2018, 79).

As outlined above, our model was formulated in the context of decision-making for children who will ultimately possess the capacities for independent decision-making in later life. By contrast, a focus on decision-making with mentally disabled children requires us to take account of the problematic feature of current legal understandings of capacity (Donnelly 2010, Clough 2018) and to strengthen the relational framing within which we reach decisions and which require support (Flynn and Arstein-Kerlake 2014; Arstein-Kerlake and Flynn, 2016; Harris, 2016). While Feinberg's model of a child's right to an open future remains central to our conception of embodied integrity, the fact that children like Ashley or young women like Anne may never obtain levels of competence required by legal tests embedded in the *Gillick* ruling<sup>17</sup> or the Mental Capacity Act point to the need for greater support in decision-making (Donnelly, 2017), which must respect the individual's 'will and preference' as required by the CRPD (Bantekas et al 2018).

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<sup>17</sup> *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112.

In seeking tentatively to bring our model into conversation with the social model of disability and the legal requirements of the CRPD, we suggest that four aspects have particular purchase in the lives of children with profound disabilities. First, and in line with our claim that bodily integrity discourse renders harms visible, we contend that an embodied integrity approach highlights how disabled embodiment is cast as inherently problematic, improper or wrong. Secondly, it mandates that we reason *from* the body and lived embodied experience, rather than reason *about* bodies in a detached and disembodied way (Williams and Bendelow 1998). Thirdly, our model recognises that humans are inevitably relational. Yet, importantly, and notwithstanding the dependency of the disabled child upon her family, it stresses the necessity of disentangling her rights from those of her parents, thereby contesting notions of family integrity which often underpin these discussions. Consequently, valuing the child's embodied integrity recognises her as a rights holder, and obligates us to support her to articulate or assert those rights. Finally, our focus on the child's right to an open future as a key aspect of her embodied integrity holds notwithstanding the reality that impairment may mean that future life is non-normative. Accordingly, and as raised particularly acutely by the case of the profoundly disabled child, the question is what open to that particular child. We now consider these features of embodied integrity in turn, before summarising the implications for legal responses and suggesting how law can play a more productive role in the lives of profoundly disabled children.

a) *Challenging the Negation of Disability*

Disability theorists have long contested the 'negation of disabled embodiment' (Overdue 1999, 17) and manner in which the lived experiences of disabled people are routinely discounted, with their bodies understood as medical lack or absence (Leder 1990). This is counterposed to the 'explicit privileging of wholeness, independence and integrity demanded of the able bodied subject' (Shildrick 2005, 757). As Overdue notes, one consequence is that the physical body of the disabled person is constituted as an object, rather than 'a lived body with an embodied self that lives and breathes, perceives and acts, speaks and reasons' (Overdue 1999, 18). Not only is the disabled body objectified, but it is coded as problematic or improper in line with Garland-Thomson's contention that disability is constituted as a 'state of corporeal inferiority' (Garland-Thomson 2002, 4-5). Relatedly, as we noted above disabled people are rendered 'forever visible and problematic, never able to disappear into the background because of their body particularities' (Moser 2005, 677) or to be 'left alone' (Koll 2010). This tension between visibility and negation has very tangible consequences in reasoning about

disabled bodies, as the Committee that unanimously sanctioned the Ashley procedures demonstrates.

Questions of reproductive autonomy or even sexual pleasure, which are simply assumed to play no part in the lives of the intellectually and physically disabled child, are similarly absent. Thus, Eve Feder Kittay, herself the parent of a child with severe impairments, observes of one prominent commentary:

Diekema and Fost take an... instrumental stance toward sexual organs. Surmising that the removal of the breast buds might reduce sexually pleasurable sensations, they promptly dismiss the worry since Ashley would never “experience sexual pleasure without being exploited or sexually abused”. Asking “what is it about becoming a woman that would be of interest to Ashley”, they write: “Most of the usual features that distinguish a woman from a girl - the opportunity to marry, procreate, work, lead an autonomous life - would not have been available to Ashley with or without a uterus, fully developed breasts, or normal stature” (Kittay 2011, 260).

Relatedly, Sullivan highlights how disabilities generate narratives of the ‘wrong body’ which are cast as central to demands to medically modify or normalise bodies. While her work concerns such narratives in the case of transsexuals or self-demand amputees, similar imperatives underpin Ashley’s case. In her parents’ claim for corrective ‘treatment’, Ashley’s body is rendered ‘im-proper’ as she grows too big and heavy to be transported easily and displays disruptive signs of ‘precocious’ puberty while being unable to value her reproductive capacity. Similarly, as we traced above, the bodies of women and girls in the sterilisation caselaw are constructed as messy or excessive, while girls in the past have been cast as excessively tall. These unruly bodies are then positioned as requiring medical management or discipline, and in extreme cases surgical correction. As Sullivan argues:

this narrativization of wrong embodiment posits a distention between mind and body, and...constitute[s] the body as im-proper, that is, as *not* the property of the subject, and conceive[s] of surgery as the means by which to overcome somatic non-ownership, to achieve integrity (Sullivan 2008, 107).

In this process, it becomes apparent how Ashley’s lived body is reduced to ‘thinghood’ - an object separate from the self (Sullivan 2008, 113). Similar processes of objectification can be

traced in cases of the disabled subjects of the early English sterilisation decisions. Such rulings allowed the surgical shaping of disabled people to accommodate the needs of others, including their carers. As with Ashley X, these decisions exemplify how, under the guise of best interests, disabled children and adults are the subject of decisions which in other contexts would undoubtedly be deemed abusive and legally impermissible. Indeed, it is difficult to identify another scenario in which law or medical ethics would sanction such radical interventions. By negating disabled embodiment the discursive technologies at play in these decisions skew the cost-benefit assessments that are said to underpin decision-making. Thus, as Ouellette and Kittay note, the harms we have outlined in relation to grown attenuation are largely ignored. In bringing together 'disabled people's presences, bodies and their flesh' (Overdue, 1999, 21) an embodied integrity approach helps challenge this negation and objectification of disabled bodies and the accompanying valorisation of liberal individualistic embodiment. It makes embodied experience central to decision-making and, while rendering disabled bodies visible, contests the view that they can be fragmented and separated from the person in ways that conventional bodily integrity discourse can allow.

*b) Reasoning from the body*

In opposition to bodily negation, embodied integrity demands that we reason from the body and assert its embodied presence (Hyde 1997) rather than absence. This challenges the 'wrong body' narrative by valuing what Read and Clements term 'the authenticity of impaired modes of being' (Read and Clements 2004, 507). Such an approach contrasts starkly with much of the literature addressing Ashley X, and with reports of subsequent cases, which make limited attempts to understand the lived reality of such lives. Rather Ashley is constituted as existing in and trapped in a state of perpetual childhood, understood in much of the academic literature and popular accounts as rendering her more manageable - a 'pillow angel'; 'forever small' - with prospects of development effectively frozen (see further Boland and Travis, this volume). As Koll observes, standard rationales and justifications for medical interventions 'rely on a very incomplete, and perhaps incorrect, understanding of the profoundly impaired child's quality of life as experienced by the child' (Koll, 2010, 259-60). She demonstrates how in practice carers and health professionals consistently underestimate the quality of life of those living with disabilities and chronic conditions. Discussions of Ashley's case echoed earlier sterilisation cases in being replete with accounts of what she lacked (Lee and Morgan 1988) – a recurrent trope in discussions of disabled persons (Moser 2005, 675). Ashley was estimated to have the cognitive ability of a 3-month-old child, notwithstanding compelling critiques of the concept of 'mental age' (Koll 2010). In line with our embodied approach, Koll

stresses the importance of reasoning instead from lived bodily experience and focusing on developmental and relational aspects of the child's life, including her potential to develop emotionally and sexually and to form relationships. Again, this resonates with scholarship in disability studies highlighting the discrimination inherent in excluding disabled persons from decisions about their lives and assessments of what they value (Fricker 2007; Series and Nilsson, 2018). As Epstein and Rosenbaum note, it "renders [children like Ashley] powerless over the fate of their own bodies" (Epstein and Rosenbaum, 2019, 108). In this regard, it is noteworthy that the pleasure that Ashley is capable of deriving was downplayed or erased in many accounts. In contrast, Edwards comments that:

she is said to enjoy changes of scenery, listening to music and family affection. She makes sounds when music plays and also moves her arms. She is said to smile and to show some recognition of her parents (Edwards 2011, 41).

Still more tellingly, at nine years old, two years after conclusion of his growth attenuation, it was reported that Ricky Prezlar was demonstrating increased purposeful movement (a key developmental milestone) and could move through the family home with a gait trainer (Field 2016).

Recognising the lived experience of those who are profoundly impaired is undoubtedly challenging, and raises difficult questions about who is best placed to interpret the 'lived reality' of the disabled child if s/he is unable to communicate it. In our view approaches grounded in embodiment are best placed to capture these realities since they recognise our place in the world as 'relational, experiential, and contingent' (Garland-Thomson, 1997 596) susceptible to change and capable of being enhanced and supported. As Garland-Thomson argues, we must attend to the 'particularity of varying lived embodiments' (Garland-Thomson, 1997 592) while acknowledging the social politics of physical difference (Kuusisto, 2012)

c) *Children as rights holders distinct from their families*

Margit Shildrick has observed how the status and meanings of disabled embodiment 'are from the start relational, rather than having autonomous standing' (Shildrick 2005, 756). Disabled peoples' lives are clearly enhanced by networks of care, and in Ashley's case her family is evidently central to her everyday life. Stories of her life depict her as a deeply loved family member and show that her family functions as a collective which sustains her. Yet, in our view

a crucial explanation for the erasure or downplaying of significant harms and risks inherent in the experimental interventions to which she was subject, was how they functioned to maintain a sense of *family integrity*. Significantly, Edwards describes how Ashley is a "bonding factor" in the family (Edwards 2008, 342), so that a central reason for seeking the procedures was to prevent her from becoming so burdensome that she could not be cared for at home. Stunting her growth ensured she remained easily portable and shielded her from being unduly distressed by menstruation. Arguably, by underlining these considerations, her parents and the ethics committee were both concerned primarily with the best interests or integrity of the family unit. This imperative to keep Ashley within the family, and the family intact, results in scant attention to arguments addressing *her* human rights, particularly those rooted in bodily integrity. In seeking to make her fit with her family the procedures she underwent entailed that, in a literal sense, her experience of 'bodily being' is constituted by [her] dwelling in a world of others (Sullivan 2008, 126). In contrast we argue that it is crucial to recognise that the interests of dependent family members may conflict with those of their families requiring limits to be placed on parental power to decide for children (Lyons 2010; Fox and Thomson 2017). This is why the child's right to embodied integrity must be the starting point for best interests assessments regarding medical treatment. At this juncture in our argument we encounter an obvious tension between individual and relational interests and rights. Our response is that in order to counter the construction of disabled people as objects - akin to pet animals to be spayed or surgically shaped for the convenience of their owners - it is necessary to prioritise the child's rights or interests in this way. Otherwise their rights risk being subsumed into those of the family or other carers (Fox and Thomson 2017). However, in recognition of the importance of sustaining the entanglement of profoundly disabled children in their family networks, and in line with the social model of disability which makes us attentive to the relationships, networks and structures in which they are situated, we shall conclude by arguing for greater state support for families caring for disabled children and adults.

*d) Child's right to an open future*

Alicia Ouellette has argued that a child's right to an open future is underpinned by the right to bodily integrity, as well as self-determination. Building on this, we have argued elsewhere that dicta in recent English cases tentatively acknowledges this point by recognising the importance of protecting a child's bodily integrity and therefore deferring irreversible non-therapeutic surgical interventions until the child can decide for herself (Fox and Thomson 2017). In order to participate in decisions, children and adults with mental impairments will need fuller support in decision-making in order reflect their 'will and preference' (Szmukler

2019). In this regard, we would argue that embodied integrity is crucial in their lives, since their more pronounced dependency renders them particularly susceptible to becoming submerged in parental projects, and even of being surgically shaped to better fit with their parents' needs and lives. Moreover, as commentators including Bridgeman (2005), Kittay (2011) and Peace and Roy (2014) highlight, it is important to simultaneously recognise limitations to what children with severe cognitive impairments may intellectually achieve, while appreciating that their interactions and experiences can develop. Interests in, and responses to, the outside world may change, just as they do for those who are not cognitively impaired. We saw above that Ashley was able to derive demonstrable pleasure from interactions and sensations. Relevant changes in her life may include preferences for and reactions to music, activities and persons, as Peace and Roy argue:

Most importantly, however, is the simple fact that children just like Ashley change over their lifespan. Their minds "progress" and change though not necessarily in a typical fashion. For example, Sophie [Roy's daughter], at 19, while eating lunch at a mall food court, expressed her significant interest in a young man walking past by gaping and dropping her fork in admiration. This is not the behaviour of a little girl or remotely like infant behaviour. Many other parents of children even more compromised than Roy's daughter report similar growth (Peace and Roy 2014, 43).

Kittay similarly talks of her daughter 'ogling' attractive men her own age (Kittay, 2011, xx). Acknowledging such potential leads us to advocate that an embodied integrity model can advance a child's interests by protecting her right to an open future, however atypical it might be. Recognising her embodied integrity, and positioning it as a central consideration in best interests assessments, in turn enhances her capacity for intimate entanglements and for change and development, while according her body a central place in these experiences. Importantly, in our view, it would rule out surgical attempts to infantilise disabled children by sterilising them and freezing them in time as 'forever small'.

### **Concluding thoughts**

Shildrick has claimed that, 'the construction of physical difference as a failing, incomplete and inferior marks disabled embodiment as deeply devalued, not so much for what it is, but for what it fails to be' (Shildrick 2005, 756). In our view the Ashley case, and the earlier sterilisation cases with which we would align it, exemplify the ongoing power of such constructions. The

sustained attention which Ashley X has attracted is partly attributable to the radical nature of the intervention, which was shrouded in secrecy and cast in earlier commentary as ‘exceptional’. In this chapter we have sought to contest its exceptionality. We suggest that significant demand exists for this controversial suite of procedures which we locate within the long history of modifying the bodies of disabled adults, adolescents, and children. In our view this suggests the need for a broader legal response to govern interventions on the bodies and in the lives of profoundly disabled children, which as for all children should be grounded in the protection of their embodied integrity.

As regards Ashley specifically, we concur with Ouellette that ‘the law failed Ashley’. It allowed her parents to alter her body profoundly and permanently for social, not medical, reasons without adequate process or oversight’ (Ouellette 2008, 209) and it failed to understand her as emergent. In a UK context, Court of Protection authorisation would be required for such procedures on over 16s, suggesting that High Court authorisation should be required in the case of children. Yet, recent cases such as the *University Hospitals of Derby and Burton NHS Foundation Trust v J (Medical Treatment: Best Interests)*<sup>18</sup> indicate that judicial oversight remains an imperfect vehicle for protecting the integrity of the disabled body. Notwithstanding the legal and cultural shifts heralded by the Human Rights Act and Mental Capacity Act, the protection of bodily integrity in UK law remains partial and incomplete. Case law contains scant reference to the CPRD and disabled adults and children continue to be subject to controversial interventions. The history of legal responses to non-consensual sterilisation suggests that interventions akin to those in the Ashley case are unlikely to be definitively ruled out in the UK.

There are, however, encouraging signs in the emerging empirical literature (Wrigley et al 2018) that such debates are increasingly couched in the language of bodily integrity. Yet, for the reasons articulated in this chapter such discourse needs to be reformulated to adequately accommodate the complexity of disabled embodiment. As Dietz has argued, legal embodiment should be reconceptualised as an ongoing process which produces normative bodies and behaviours, and shapes the conditions and possibilities for embodied resistance (Dietz 2018, 186-7). In similar vein James Overboe has argued for the validation of both a disabled embodiment and sensibility:

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<sup>18</sup> [2019] EWCOP 16

Our physical, mental and emotional manifestations of disability as well as the social, political, moral and physical environment will continue to have an impact upon us. But shifting the notion of an identity which is devalued to lived experience that is valued causes a change in approach (Overboe 1999, 23).

We see our model of embodied integrity as contributing to such a change in approach, as well as fitting within the broader turn within the humanities and social sciences to the role of embodiment in new models of social justice. Our focus on Ashley's embodied integrity, and the importance of how she is supported in society directs us to the obligations of the state. Following Epstein and Rosenbaum (2019) we would stress the importance of equipping her family with the assets or resources to care for her, so that recourse to an experimental suite of medical interventions designed to 'remake' their daughter and sister is unnecessary. Rather than prioritising family integrity, as we argue happened in the Ashley case, the focus should be on state obligations to provide for the family in the face of the significant caring responsibilities entailed by living with children and adults like Ashley and Anne. We see this as consonant with the vulnerability framework set out in this collection and elsewhere by Martha Fineman (e.g. 2010, 2011, 2013) but which we cannot elaborate on here.

Crucially, in endorsing an experimental chemical and surgical solution, standard bioethical accounts of the case omit discussion of embodiment, of social attitudes to disability (Oliver 1990; Shakespeare 2006) and of the need for a broader social strategy. In the rare instances where these issues are raised within bioethics, they dismissed as irrelevant to Ashley's case (Edwards 2011). We believe that our embodied integrity model has an important role to play in ensuring health professionals can less readily sanction interventions on children that will reduce their material bodies to legal objects to be fragmented and medically managed, since they will be called to account legally if they acquiesce in such requests. This should, in our view, be seen as a first step towards a broader social justice approach that fully respects embodied difference and supports families to realise and respect such difference.

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