

Vulnerable subjects and autonomous actors: The right to sexuality education for disabled under-18s

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Abstract

The notion of ‘autonomy’, it is argued in this article, may be better suited than the concept of ‘agency’ for framing many issues relating to the international children’s rights law framework. This is because autonomy is already the prevalent concept in the arena of legal rights for over-18s, for example in medical law. Autonomy must of course be understood in a relational way and in a way that recognises the vulnerability inherent in the human condition (Fineman, 2008). In this article, the example of the right to access sexuality education for disabled children is used to demonstrate these points and to explore the autonomy/vulnerability dynamic. Historically, sexuality education has been denied to disabled children, ostensibly to protect them from information and activities perceived as inappropriate due to their (perceived) greater vulnerabilities. It is argued however that discourses of sexual vulnerability can actually be dangerous in themselves. Sexuality education, rather than being a threat to disabled under-18s, is a way to increase their autonomy rights by equipping them with tools of knowledge around sex and relationships. This case study demonstrates how the autonomy of under-18s is not something inherent in them, but something which can be enhanced through recognition of rights such as education and information; as well as recognition of adult responsibilities to facilitate this.¹

Keywords

Children’s agency; children’s autonomy; UN Convention on the Rights of the Child; vulnerability theory; disabled children; sexuality education.

Introduction

The concept of ‘agency’ is prominent in the field of childhood and youth studies, and has been hugely important in redefining research across different disciplines (Bordonaro and Payne, 2012). Scholars and practitioners now refer frequently to children and young people as ‘social agents’ (see e.g. Notermans et al., 2011). This notion of agency perhaps mirrors neatly the ‘participation’ element to be found in the UN Convention on the Rights of the Child (CRC). There are problems however with the vagueness of both terms for under-18s when it comes to understanding and claiming their rights, and in particular their legal rights to make choices for themselves (Daly, 2018).

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In this article therefore it is argued that ‘autonomy’ is a preferable term when it comes to framing such rights. This is because autonomy is already the prevalent concept in the arena of rights for over-18s, for example in medical law. Autonomy is sometimes a philosophical ideal, and sometimes it is a legal right (the legal right to consent to medical treatment, or to consent to sex, for example). Yet it is broadly understood to denote the human urge to determine our own destinies, particularly when it comes to our intimate lives and decisions about our own bodies. To challenge idealised and unrealistic visions of childhood requires acceptance that under-18s have autonomy rights as adults do. Under-18s should only be viewed as requiring ‘protection’, where this means overruling their own choices, where this is truly necessary and proportionate (Daly, 2018).

Autonomy must be understood in a relational way, however, in order to avoid the pitfalls of unduly idealising the liberal individual. This point is in line with and sympathetic to emerging arguments that prioritising ‘agency’ risks over-emphasising the liberal individual (Rimmer, 2017; Bordonaro and Payne, 2012). Understanding the vulnerability inherent in the human condition (Fineman, 2008) is crucial. Therefore the autonomy of under-18s should be placed in context. Appreciation is needed for the crucial position of family, friends and communities in the wishes and decisions of children and young people, and due regard must also be had for the extent to which education, information and other support will maximise the potential for autonomy (see e.g. Daly, 2018).

In this article, the example of the right to sexuality education for disabled under-18s is used to demonstrate these points. ‘Sexuality education’ is understood here broadly to refer to education and information from various arenas on sex, sexuality and relationships. Historically, such education – typically manifesting as a state activity or obligation within the context of school – has been denied to disabled people generally and disabled under-18s in particular. Perhaps ironically, this has primarily been on the basis that disabled people need ‘protection’ from knowledge of sexuality, and from engagement in sex. It is argued that adults frequently focus unduly on vulnerability (disregarding the potential for autonomy) and tend to err on the side of (ostensibly) ‘protecting’ under-18s (i.e. excluding them) rather than recognising and facilitating their autonomy rights. Normative, neoliberal adulthood is revered, and it is therefore challenging to recognize that disabled under-18s will have intimate lives, and that they will therefore require information and education on sex and relationships.

This article brings together the strands of children’s autonomy, disability and sexuality education, providing interdisciplinary analysis through a children’s rights framework. It is globally focused although approached from the perspective of the liberal democracy. We draw upon examples from the UK context in which the researchers are situated to consider the positions and perspectives of disabled under-18s. We are focusing on under-18s primarily because this is the distinction between childhood and adulthood for most purposes, but also because so much of the research conducted around disabled people and sexuality focuses on over-18s, and neglects childhood. We are theorising generally about under-18s with disabilities of all kinds.

It is argued in this article that discourses of sexual vulnerability can actually be dangerous in themselves. Sexuality education, rather than being a threat to disabled under-18s, is – amongst other things – a way to increase their autonomy rights by equipping them with tools of knowledge around sex and relationships. The fact that sexuality education will likely boost decision-making demonstrates how the autonomy of under-18s is not something inherent in

them, but can be enhanced through recognition of rights such as education and information; as well as through recognition of adult responsibilities to facilitate this. It is argued that recent theory emerging from disability studies can challenge the rigid autonomy/vulnerability divide in positive, constructive and transformative ways.

The first section of this article considers the various terms and concepts of agency, autonomy and vulnerability. In the second section, it is highlighted that disabled people, and particularly under-18s, are frequently seen as 'other' in a world prioritising the liberal individual. There is an insistence on the 'vulnerability' of disabled people, and they are consequently seen as sexless and as not suited to sexuality education, due to a commonly held belief that they should not be engaging in sexual activities and relationships. After this consideration of the academic theory relating to disabled people and sexuality which has recently emerged, the third section involves a closer examination of the nature of sexuality education, and how it is failing disabled under-18s. It is argued that sexuality education is a means of overcoming vulnerability, demonstrating the fluid nature of the autonomy/vulnerability divide. It is also argued that having to consider the rights and interests of disabled under-18s in this context will benefit all humans, by encouraging a rethink of gender and sexual norms.

1. 'Agency' or 'autonomy' in children's rights?

Agency: Children as social actors

There has been a distinct transformation in the past three decades in how under-18s are viewed in both the social sciences and the legal arena alike. The work emanating from the 'new social studies of childhood' has portrayed under-18s as competent social actors. It has emphasised that under-18s have the capability to influence their environments independently of adults; that they have 'agency'. Oswell's (2013: 3) conception of agency is that: 'children are not simply beings, they are significant doings. They are actors, authors, authorities and agents. They make a difference to the world we live in'. Children have been framed as 'active in the construction of their own lives, the lives of those around them and of the societies in which they live' (James and Prout, 1990: 8). Many empirical studies have also emphasised the ways in which under-18s work as competent social actors, displaying 'agency' to various degrees (Hutchby and Moran-Ellis, 1998).

There has more recently been some reflection on the point that notions of 'agency' incline, albeit unintentionally, towards the liberal individual (Rimmer, 2017; Bordonaro and Payne, 2012). This deification of the liberal individual is based on prioritising the 'exercise of rationality and intentionality, self-awareness and reflectivity, competence, strategy and efficacy' (Rimmer, 2017: 560) as something to which we should all aspire, including under-18s. This perhaps implies that children's problems will be solved if they could just be more like the rational, white, adult, minority-world ('Western'), male.

'Agency' is also problematic in its normative element, in that when under-18s are seen as 'doing the wrong thing' (for example engaging in crime, sex or in working activities) their agency is no longer subjected to empirical verification but is instead deemed 'impossible by definition', revealing some of the conceptual weaknesses of the concept of agency and what should be considered 'right' and 'wrong' in relation to under-18s (Hansen, 2016: 474). It has been pointed-out that the notion of agency may be used, or employed for various projects or programmes, without an appreciation of what it might mean in contexts where under-18s engage in 'undesirable' activities; activities which are at odds with our idealisation of

childhood ‘innocent victims’ (Bordonaro and Payne, 2012). Privileged children – those who are less likely to engage in criminal behaviour or other undesirable activities – will therefore likely be perceived as better suited to agency than disadvantaged children (Valentine, 2011: 355).

It is also increasingly argued that children’s agency must be reconceptualised in childhood studies; so that it is recognised that agency is located in social relations and interdependency (Esser et al., 2016) and that, rather than being a quality a person has or does not have, it emerges in the practices in which children engage (Hansen, 2016: 474). All of these points also apply to a nuanced conceptualisation of the notion of ‘autonomy’.

Autonomy: A philosophical and legal concept

‘Agency’ is a term which seems to have primarily emerged from and been explored in the social sciences rather than within the children’s rights component of domestic and international human rights law. It is the term ‘participation rights’ – arising from CRC Article 12 – which has been the main focus for human rights law in terms of recognising the ability of under-18s to contribute to their own lives and to shape their environments. However there is a distinct vagueness to what a ‘right to be heard’ or ‘participation’ means in terms of the part which under-18s play in the direction of their own lives. In international human rights law ‘participation’ generally refers to the part that under-18s are *permitted or facilitated by adults* to play in their own lives, as in this arena participation is usually examined or discussed in contexts where adults are determining the legal rights and interests of under-18s. The result is that, when it comes to the undesirable activities of under-18s, discussions of ‘balancing participation and protection’ abound, arguably with few concrete solutions emerging. Daly, 2018 argues that this is particularly the case when it comes to the role of under-18s in decisions about their own person (as opposed to civic or political participation).

The participation concept is open to a range of interpretations, covering instances of the involvement of under-18s ranging from significant to minimal (Alderson and Montgomery, 1996: 27); possibly even tokenistic (Lundy, 2018). Therefore what is meant by the term ‘participation’ is, on the face of it, often unclear. The extent to which participation requires any particular level of influence or quality of process or outcome is also in question, though some now argue that *influence* must be a prerequisite for something to be considered participation (see for example Vis and Thomas, 2009 and Bessell, 2011: 497) and many authors have analysed what participation should mean in a particular instance – Lundy for example emphasises that “[w]hen the decision affects an individual child, tokenistic approaches will always be wrong” (Lundy, 2018: 350). Nevertheless it has been argued that CRC Article 12 and the participation discourse (Hammarberg, 1990: 100) has a monopoly in children’s rights which has distracted from the mainstream civil and political rights framework which applies to adults (Quennerstedt, 2010: 631–632). So too has it distracted from asserting and theorising children’s autonomy rights (Daly, 2018); rights which are accepted as fundamental for adults; the overriding of *adult* autonomy (for example depriving of liberty, or forcing medical treatment ‘in their own interests’) is treated with the utmost seriousness.

‘Autonomy’ can mean different things in different contexts. It can be seen as ‘the ideal that we should all have personal freedom in our lives to the extent possible’ (see Daly, 2018: 116). ‘Personal autonomy’ is understood as the individual’s capacity for self-governance. Autonomy can also be the capacity to make decisions, including the legal right to take those

decisions (for example capacity to consent to medical treatment). Yet the word autonomy evokes a relatively clear message – it denotes a natural human desire to determine our own future. Unsurprisingly there is extensive evidence that autonomy is inherently good for individuals. Empirical work indicates that we deeply value having a feeling of control over our own destinies, and that children and young people generally fare best across all measures (academic, emotional etc.) when they receive autonomy-supportive parenting and education (see e.g. Froiland, 2015; Deci and Ryan, 2014; Deci and Ryan, 2000). Such an approach involves supporting children and young people to explore their environment and to take an active role in solving the problems which they encounter; and it stands in contrast to controlling approaches involving commands and restrictions (Pomerantz, Grolnick and Price, 2005: 261).

Autonomy is consequently the most valued characteristic for the individual in a liberal democracy (Oshana, 2014, at 214). There are laws upholding autonomy and social policies are based around it. The international human rights law framework is also based on prioritising the dignity and therefore the autonomy of the individual in the face of state power (Freeman, 2010: 215).

Yet, outside of (and perhaps even inherent in) laws upholding it, essentially autonomy is just an ideal. No-one is truly autonomous as our well-being is rooted in our relationships with those around us, and we are all constrained in our autonomy by factors such as finances and abilities. This is the case for both adults and under-18s in reality, but nevertheless the law generally assumes that adults are autonomous and that under-18s are not. Standards such as legal minimum ages create and reinforce this situation (Daly, 2018). It is assumed that under-18s do not have the cognitive capacity (i.e. abilities relating to knowing, judging and evaluating) to make decisions, though the reality is that under-18s are often capable and adults are often vulnerable (Daly, 2018: 116).

It is increasingly argued therefore that greater fluidity is needed in how the law conceptualises the autonomy of adults and under-18s (Daly, 2018), with some arguing that the law must take a more paternalistic approach to adults who are vulnerable, yet legally autonomous (see e.g. Herring, 2016). Children need not have identical legal autonomy rights to adults. Yet it is argued that a different approach is required and possible in areas of the law which may involve denying children's personal autonomy. Under-18s should enjoy autonomy where possible, for example where courts are making decisions on their behalf (Daly, 2018).

A relational approach must be taken of course, as most under-18s prefer to make such decisions together with those whom they trust – our decisions are rooted in our relationships with others. Feminist theorists emphasise the fact that social relations are necessary for the realisation of autonomy (Friedman, 2014) and that a web of relationships influence a person's decision-making abilities (Herring, 2011: 40).

That said, it must be recognised that in some circumstances under-18s, as adults, feel strongly about what they want and great distress when they do not get it. Many cases involving this point are outlined in Daly, 2018, for example *Re J.S. (Disposal of Body)* [2016] EWCH 2859 in which the estranged father of a dying 14 year old was attempting to impede her plans for her body after death, and in which the court noted that following the girl's plans would decrease her: 'agitation and distress about her impending death' (para. 13). Autonomy is not

simply about getting whatever one wants; it is also about respect for the dignity of others, including under-18s.

Autonomy is also about being supported to be involved and to make decisions on matters concerning oneself including through information and education. It should not mean a *laissez-faire* attitude devoid of an ethic of care (Childress, 1990). The types of autonomy support, outlined above, is therefore crucial – rather than being abandoned to make decisions alone, children should be supported with information and other assistance whether it comes to a decision in the legal realm, or elsewhere (Daly, 2018). Talking about autonomy should be as much about adults' obligation to respect under-18s as individuals, then, as it is about the right of under-18s to determine their own future. This element of autonomy – that it is something which must be nurtured and facilitated, rather being static in the individual, is crucial to its relationship to vulnerability, not least because the more 'vulnerable' a person is, the more likely they are to require autonomy support.

Vulnerability, disabled children, and the right to sexuality education

The term 'vulnerability' is one that is commonly associated with under-18s as opposed to adults, and is regularly cited as a reason why under-18s should not enjoy rights (Herring, 2012). It is also used as justification for a particular 'protection' approach to under-18s in law and practice.

The heavy protection theme of the CRC reflects the perception in law and in popular discourse of the vulnerability of under-18s, though the term 'vulnerability' does not appear explicitly in that instrument. Concern for the perceived vulnerability of under-18s is also to be seen clearly at domestic level – the 'welfare principle' in the Children Act 1989 and in the laws of other common law jurisdictions for example "is often supported in the name of protecting children" (Herring, 2012: 43). In relation to sexual abuse and exploitation, it is inarguable that under-18s are particularly vulnerable. There is generally speaking an obvious power imbalance between children and adults and children therefore must have some element of special protection to account for this. But risk is not exclusively a *children's* problem. Herring 2012 argues that the emphasis on the vulnerability of children "is part of an attempt to hide from the vulnerability of adults. It helps bolster the image of the autonomous independent man" (Herring, 2012: 63). We must distinguish between the denial of autonomy where under-18s genuinely need protection on the one hand from unjustifiable paternalism on the other (Daly, 2018).

Increasingly there are calls in academia to recognise our common vulnerabilities. Fineman (2004: 227) argues that we are all subject to vulnerability in many areas of life (because of advanced age, or global financial crises, for example) and that the focus of law should be on the vulnerable individual rather than the autonomous liberal individual (see also Tobin, 2015: 157). A failure to recognise vulnerability permits the state to shirk responsibilities, and results in substantive inequalities and the allocation of privilege to the powerful. This is particularly relevant for under-18s – perceived as the opposite of the rational, competent, invulnerable adult. Herring argues that vulnerability need not be seen as an inherently negative thing, instead urging us to embrace it as part of the human condition (Herring, 2016: 1). Fineman urges that greater equality and democracy can be achieved by accepting that we all need support (Fineman, 2008: 19-20).

Vulnerability is a fluid state, of course – information and education will make a difference. Disabled children are seen as a vulnerable (or perhaps inconvenient) group when it comes to sexuality education and therefore may be excluded from it altogether, rather than receiving information tailored to their needs, a point addressed more substantively below. Tisdall opines that understandings of child protection frequently fail to address structural issues, focusing instead on interpersonal relationships such as those between under-18s and exploitative adults (Tisdall, 2017: 60). Similarly the structures surrounding how and whether disabled under-18s can access sexuality education is crucial. Under-18s must be involved in “identifying their own concerns and solutions” (Tisdall, 2017: 60) in sexuality education as in other areas, as considered further in Section 3.

It should be noted that there are of course numerous types of disabilities and these can range from having mild to profound effects on children’s lives. Due to the confines of this article we are being general here. We encompass all disabled under-18s in our central point – that sexuality education, rather than being a threat, is a way to increase autonomy rights (and therefore decrease vulnerability) by equipping under-18s with tools of knowledge around sex and relationships.

2. Sexual autonomy, youth and intimate citizenship: Constructing vulnerable subjects

Disabled children and young people; Viewed as primarily vulnerable?

Sexual autonomy is a powerful ideal in cultures and contexts where disablism and ableism thrive, and where normative neoliberal adulthood is revered (see Liddiard, 2018). Campbell (2009: 44) defines ableism as a ‘network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human’. Ableism is embedded in Western humanist and capitalist values, which demand ability, sanity, rationality, physicality, cognition and autonomy – the universal human defined in the liberal tradition (Fineman 2008: 10) – as integral to both the human condition and social order (see Braidotti 2012). Such values denote a compulsory ‘ableness’ (McRuer, 2006: 9): the idea that ‘able-bodied identities, able-bodied perspectives are preferable and what we all, collectively, are aiming for’. Disablism, however, is the resultant oppressive treatment of disabled people – discrimination, prejudice, exclusion, marginalisation, and a denial of access to multiple areas of private, community and public life and participation in civil society. When we use the term dis/ableism, we are referring to the iterative processes of ableism and disablism, which ‘casts [disabled people] as a diminished state of being human’ (Campbell 2009: 44).

In dis/ableist cultures, disabled people are routinely denied access to their sexual lives, selves and bodies, across multiple areas of their lives (Liddiard, 2018). As a marginalised group, they experience ‘institutional and legal restrictions on their intimate contact’ (Siebers, 2008: 136). Characteristically refused social and sexual power, agency and autonomy, disabled people experience an absence of rights to what Plummer (2003) calls intimate citizenship – that which ‘concerns our rights and responsibilities to make personal and private decisions about with whom and how we are in intimate relations’ (Ignagni et al. 2016: 132). In the context of under-18s, intimate citizenship becomes even more difficult to claim, as the impacts of infantilisation, developmentalism, protectionism and desexualisation construct disabled young people as either sexless and/or hypersexual. This binary means that there can be a failure to provide disabled children and young people with the education, information or safe spaces needed to carve out a desired sexual selfhood and identity. There can be an

‘erotophobic approach’ which can lead to hierarchies based on attributes such as age, and physical and mental ability (Wilkerson, 2002: 41). Thus, in the contexts of childhood, youth and disability, sexual and intimate relations are confined and contained according to an ableist imperative that dictates normative desires, practices, behaviours and ways of being (see Liddiard and Slater 2017). This effectively excludes disabled children and young people ‘from most of the dominant socialisation processes that help teach and prepare people for love, sex and intimacy’ (Davies, 2000: 181).

Historically, sexuality education has been denied to disabled people, as outlined further below. Where sexuality education *is* offered to disabled young people, it has been criticised by disabled scholars for its focus on normative bodies and normative bodily experiences, which can serve to alienate and further marginalise disabled children and young people, as well as propagate dis/ableist myths such as ‘disability implies asexuality’ (Thompson et al. 2001: 59; see also Davies 2000 and Shakespeare et al. 1996). It is also critiqued for generating raced, cis-gendered, heteronormative and dis/ableist expectations of what it is to be or *become* adult (Liddiard and Slater 2017).

Rather than serving to protect, then, discourses of sexual vulnerability ascribed to disabled bodies, minds and selves can materialise as danger in the lives of disabled people. As part of the dis/ableist justification that disabled people are too vulnerable and/or at risk to negotiate the sexual realm, critical knowledges, forms of (accessible) information, and sexual support – as well as the necessary space and access to sexual and intimate life – are habitually disallowed. Paradoxically, this is argued to *increase* disabled people’s sexual vulnerability, particularly for those with the label of learning disability, disabled women and disabled people who identify as lesbian, gay, bisexual, and/or trans (LGBT) – in effect putting them at a greater risk of sexual abuse and violence (Hollomotz 2011). Neoliberal-able (Goodley 2018) and individualist notions of vulnerability exacerbate this problem, placing the onus on the individual rather than ‘the institutional arrangements of domination and subjugation’ (Zavirsek, 2002: 270) that determine disabled people’s bodies as sites of violence. Ironically, the vulnerability label may serve to render disabled children and young people even more vulnerable; putting them at greater risk where they are denied information, education and space to learn and experience.

Troubling the human: Disability and desire

Through disability, however, we may in fact be able to reframe thinking about the intimate lives and knowledge of under-18s. Goodley and Runswick Cole (2014: 3) argue that disability has ‘the radical potential to trouble the normative, rational, independent, autonomous, subject that is so often imagined when the human is evoked’ – bringing into view a new politics of vulnerability.

Such a position offers the potential to see value in and the collectivity of vulnerability; to move from associating it with victimhood and to reclaim it ‘for its potential in describing a universal, inevitable, enduring aspect of the human condition that must be at the heart of our concept of social and state responsibility’ (Fineman, 2008: 8). Vulnerability can instead be an arena for ‘human exchange, empowerment, and growth’; necessary for human being and human understanding (Rice et al., 2015: 520). It can offer ‘alternative ways of conceptualizing the human subject’ (Braidotti, 2003, 2006, 2013: 37) and be embedded in the posthuman condition. This will insist that we consider alternative kinds of citizenship and ways of being human (Liddiard, 2018: 163).

Pulling disability politics into posthuman theory, Goodley et al. (2014: 358) put forward the DisHuman – ‘a mode of understanding that simultaneously acknowledges the possibilities offered by disability to trouble, reshape and refashion the human (crip and posthuman ambitions) while at the same time asserting disabled people’s humanity (normative and humanistic desires)’. Disabled people are fighting to be recognized as humans, and in the process are engaging in activism and art which pushes us to think imaginatively and critically about the posthuman (Liddiard 2018: 163).

Disabled people’s exclusion from the category of the Human affects their sexual and intimate lives on a number of levels; compromising their entry into normative sexual categories. It resists their sexual agency and their calls for rights relating to sexuality (Goodley et al. 2015: 11). Yet disability can be a transformative element in normative constructions of sexual ableness, ability and humanness: disabled bodies and minds contest prevalent myths of the sexual body as self-governing autonomous, contained and in control (see Slater and Liddiard 2017). Disabled bodies quite often require sexual support and assistance in ways that challenge sexual normalcy: ‘the (Crip) sexual body emerges as a space of (embodied) relationality and interconnectedness, corporeally interwoven with other bodies and selves in multiple and creative assemblages’ (Goodley et al. 2015: 11). Therefore, DisHuman and posthuman modes of thought draw upon ‘disability to invoke (emancipatory) posthuman modes of sex/uality which value (and celebrate) inter/dependence; queer; radical relationality, collaboration and collectivity in ways that can be emancipatory for all sexual subjects’ (Goodley et al. 2015: 12).

Therefore requiring systems to accommodate sexuality education and information for disabled children will likely have the positive effect of challenging normative constructions of sexuality. This will, in the process, educate teachers, students, policy-makers and others about different experiences, needs and wishes when it comes to relationships, sex and education. It will insist that we think outside the box about what sexual normalcy is.

3. Sexuality education, vulnerability and disabled under-18s

It is necessary to consider what sexuality education is, how it is failing disabled under-18s, and what a transformed approach to sexuality education should involve. Although a detailed proposal for the content of children’s rights-based sexuality education for disabled under-18s is beyond the scope of this article, some key components of how to get there – a rights basis; child-lead curricula; and a rethinking of sexuality from the perspective of disability, for example – will be outlined.

Sexuality education for disabled under-18s: Accessibility and content

International human rights standards are clear that children and young people have a right to sex education. The UN Committee on Economic, Social and Cultural Rights is the implementing body of the International Covenant on Economic, Social and Cultural Rights, which enshrines the right to the highest attainable standard of health (Article 12). The Committee states that Article 12 obliges states to ensure that:

...[U]p-to-date, accurate information on sexual and reproductive health is publicly available and accessible to all individuals, in appropriate languages and formats, and to ensure that all educational institutions incorporate unbiased, scientifically accurate,

evidence-based, age-appropriate and comprehensive sexuality education into their required curricula (UN Committee on Economic, Social and Cultural Rights, 2016, para. 63).

The (almost universally ratified) CRC states in Article 17 that children have the right to access information aimed at the promotion of their health, and in Article 24 that states have the obligation to develop preventive health care, education and services. The Committee on the Rights of the Child emphasises that children have the right to “age-appropriate, comprehensive and inclusive sexual and reproductive health education, based on scientific evidence and human rights standards” and that special consideration should be given to disabled children (Committee on the Rights of the Child, 2016, para. 61). States who have signed-up to these instruments have agreed to abide by them. They are, after all, minimum human rights standards. Some countries like the UK (those with ‘dualist’ legal systems) have not yet enacted the necessary domestic legislation which would permit these international treaties to become legally enforceable in courts. However judges do sometimes rely on these international standards in interpreting domestic law (see e.g. *ZH Tanzania v SSHD* [2011] UKSC4). With the advent of children’s rights in the past three decades, it is unsurprising that there is broad international acceptance that sexuality education is a human right, and research shows that sexuality education has become the norm throughout Europe and Central Asia (Federal Centre for Health Education, 2018), which at the very least shows that its importance is broadly recognised at domestic level too.

Much of the problems of implementation of international human rights standards lie in the interpretation of what those standards entail. Neither ‘sexuality’ nor ‘sexuality education’ have specific definitions, but the latter encompasses several components: *sex* (with a focus on biological characteristics); *relationships* (with a focus on sexual/romantic relationships and interactions); and *sexual health* (with a focus on health outcomes and issues relating to sexuality) (Ponzetti Jr, 2015: 2-3). In other words, it goes beyond mere technicalities of sex, to encompass “attitudes, feelings, rights, and responsibilities” as well as how people “[understand] themselves as sexual beings in societies that hold particular views about how and when sex should happen, between whom, and at what stage of one’s life” (Crewe, 2015: 100).

Importantly, sexuality education takes place across a variety of settings – in school, in the family home, amongst friends, on the Internet, television, music, magazines, religious organizations, through personal experiences, and more (Macdowall et al., 2015; Tanton et al., 2015; Ponzetti Jr, 2015). It also takes place across the life-course of the individual, including in school (Ponzetti Jr, 2015), although of course parents, peers and other arenas such as the Internet will be key in the learning of children and young people.

Sexuality education is often denied to under-18s, borne out of a fear ‘that knowledge of sexuality will make them immoral, more sexual, and adult before their time’ (Olsson, 2016: 295). This relates inherently to the idea that under-18s are ‘vulnerable’ and unable to make the ‘right’ decisions in relation to the exercise of their sexuality. Consequently, they should be protected from sexual knowledge until they become ‘capacious’ adults.

If sexuality education is contested for children and young people in general, it is even more problematic in the context of *disabled* under-18s. The perceived asexual or alternatively hypersexual nature of some disabled under-18s means that sexual activity or expression is often discouraged and prevented by parents, guardians or carers (Travers et al., 2014). It is

often assumed that sexual knowledge which opens up possibilities for such activity should also be prevented, ostensibly to protect under-18s from becoming exploited, or from becoming sex offenders (Gomez, 2012; Björnsdóttir et al., 2017). It has been shown that disabled people receive less sexuality education (Björnsdóttir et al., 2017; McDaniels and Fleming, 2016). It has been found that there can be a sense amongst those caring for disabled people that it is ‘someone’s else’s job’ to provide this education, and indeed it has been suggested that a co-ordinated approach from a combination of school, health professionals, and parents is necessary for those with physical disabilities (East and Orchard, 2013). It has been demonstrated that disabled children have less knowledge of sexual matters, such as puberty and safe sex practices compared to non-disabled peers (Galea et al., 2004; Murphy and Young, 2005).

Of course, the right of parents to withdraw their children – to ‘opt out’ – from sexuality education is a prominent matter in the arena of sexuality education. The right for parents to withdraw persists to a large extent, for example in the UK (see e.g. Department of Education, 2018: 7). Although it is a fundamental parental right to determine the nature of their children’s education, it has been argued that it is proportionate to override parental preferences in the instance of sexuality education (Campbell, 2016). In the words of one teacher of disabled under-18s: ‘Our guys can’t opt out of puberty’ (see Williams, 2015). It is likely that parents of disabled children may be particularly worried about the appropriateness of sexuality education. This makes it all the more crucial to insist on framing such education as a means of decreasing vulnerability, as well as providing the tools to form positive relationships.

It is not just the accessibility of sexuality education, but also the content, which fails many disabled children. In her participatory research with disabled young people, Liddiard (2018: 61) found that learning about sex and sexuality is generally done through a lense of dominant expectations of ableist sexual normalcy. These dis/ableist constructions of disability and sex/uality shape the extent to which disabled young people learn about sex and intimate relationships, with the result that disabled people may internalise feelings of otherness. For example here Terry, a 20-year-old man with a disorder involving muscle weakness recalls learning about sex/uality in school. The lesson was focusing on how to put a condom on:

I remember saying – ‘to be fair you’re talking to someone who can’t even open a chocolate wrapper, so I haven’t got much hope, have I?’ I remember it was almost like a shock because he [teacher] said ‘does that mean you’re not going to use contraception?!’ and I said ‘well no, obviously I’d just ask the other person to put the condom on...’ (Liddiard, 2018: 56)

Liddiard states that this indicates that, even in education ostensibly tailored to people with a specific disability, learning can be defined by how disabled people’s experiences deviate from the ableist sexual cultures and practices which are dominant. These kind of exclusionary approaches can further myths that disability implies asexuality, and education can in fact serve as a means of reproduction of the otherness of disabled people.

Sexuality education as a means of overcoming vulnerability

Sexuality education, rather than being a threat to disabled under-18s is, amongst other things, a way to increase their autonomy rights by equipping them with tools of knowledge around sex and relationships. The UN Special Rapporteur on the Right to Education emphasises that

sex education ‘provides the tools that are needed for decision-making in relation to sexuality corresponding to the lifestyle which each human chooses in the context of her situation’ (UN Special Rapporteur on the Right to Education, para. 17).

Effective, comprehensive and appropriate sexuality education equips children and young people with sufficient knowledge and understanding to navigate the waters of sex and relationships, exercise autonomy and make informed choices, and exercise their sexual rights (Crewe, 2015; Galea et al., 2004). It provides them with the language to describe and report incidences of sexual abuse, and breaks down taboos around discussing sexuality – which prevents such reporting (Gomez, 2012). Sexuality education curricula can also address issues like body image, self-identity and self-esteem, which often undermine the confidence of children and young people with disabilities (Gomez, 2012). As such, effective sexuality education is capable of eradicating some of the existing barriers to the exercise of sexual autonomy and expression by people with disabilities, and is a necessity for sexual ‘self-determination and self-advocacy’ (Travers et al., 2014: 233). Although information on positive relationships and on staying safe is obviously relevant for everyone, and for all disabled under-18s, it is particularly important for girls because of the nature of gender relations (see e.g. Campbell, 2016: 1221).

In other words, access to sexuality education is important to reduce sexual vulnerability and promote resilience (Tobin, 2015: 170). It is impossible to eliminate all vulnerabilities and risks inherent in the human condition (Fineman, 2008), yet educating and empowering children and young people to understand and assess risks, and to take action to protect themselves (Shier, 2010: 33), is crucial.

There are clear problems of accessibility and content plaguing ‘traditional’ sexuality education routes for disabled under-18s. There is a need to consider, particularly in a context such as England and Wales, where sexuality education is being re-thought (Heah, 2018), how to carve-out a space for assumptions that, amongst children in all of their diversity, disabled children will be one group who will absolutely need, to some extent at least, a curriculum specific to them. Within this cohort of course, there will be the need to break-down education further in accordance with age and different disabilities. Whilst the Department of Education Guidance on sexuality and relationship education (2018) makes reference to the needs of disabled children it is seriously lacking. The Guidance states that disabled children will require teaching that is differentiated and personalised when it comes to sex and relationships, however there is little detail on how teaching and learning can and should be personalised for pupils within schools (paras 30-32). The Guidance also refers to ‘exceptional circumstances’ in which a disabled child’s special educational needs will be taken into account when making a decision on the parental right to withdraw their child from sexuality and relationship education (para. 44), without giving examples of such circumstances, which runs the risk of disabled children unduly being removed from such lessons.

Forms of delivery outside of school and the family will be crucial. Currently, the Internet is a prominent source of sexual advice and education amongst children and young people (Simon and Daneback, 2013) not least because it is generally affordable, available, anonymous, and private (Barak and Fisher, 2002). Further, an Internet-based model for teaching sexuality education has the potential to be interactive, specific and individualised (Barak and Fisher, 2001: 330). In relation to disabled under-18s in particular, online sexuality education could provide several additional benefits – firstly, in that they would open up access to sexuality education where none such may have existed before, but secondly and more importantly, in

that they may allow such education to be tailored to the *specific disabilities* of the individual. Hence, this could potentially overcome some of the problems arising from the current lack of specificity when it comes to sexuality education for individuals with differing types and degrees of disabilities. More research is required to consider access issues and other specific risks for disabled under-18s. It should not be assumed however that disabled under-18s are more susceptible than others to online risks, or that they have less ability to cope with adverse online experiences (Chadwick et al., 2017).

It is not just the content and development of curricula which require attention. A rethink is needed around the extent to which they are resourced, and how to deal with structural discrimination when it arises. This should be approached in a rights framework. The Committee on the Rights of the Child, in emphasising the state obligation to provide sexuality education, state that the necessary human, financial and technical resources should be provided to design and implement such programmes (Committee on the Rights of the Child, 2015, para. 59). Furthermore that instrument recognises state obligations regarding the special needs of disabled children in Article 23. The UN Convention on the Rights of Persons with Disabilities emphasises that states must “take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children”. At a recent event at the University of Liverpool on sexuality education for disabled under-18s, the issue of resources, and the discretion which schools have concerning how and whether they implement sexuality education was a prominent, perhaps *the* most prominent theme (see European Children’s Rights Unit Briefing, 2018). This is particularly significant in countries in which dramatic cuts to public services have been enforced, including in the education sector. The knowledge of children and young people about their sexuality should not be dependent on whether schools wish to prioritise it.

There are many ways in which sexuality education could be tailored to account for the needs and common characteristics of groups with particular disabilities. It was found by Schaafsma *et al.* that, for adults with cognitive impairment interviewed in the Netherlands, the frequency of sex education sessions appeared to be low, as participants did not remember having received sex education. They make the point that continuous sexuality education will be necessary for people with ‘intellectual disabilities’ in order to maintain high levels of knowledge. (2017, 32-33).

It is also important to note that East and Orchard (2013) have found that what literature exists indicates that the majority of sexuality and disability research tends to be focused on sexuality education for youth who have cognitive impairment, while often disregarding the experiences of people with physical disabilities that do not affect their cognitive functioning. They theorise that this is due to a fear of sexual abuse and exploitation of those with cognitive impairment. What this perhaps indicates is heightened attention to the vulnerability of certain subgroups of disabled people, and simultaneously neglect of the rights and needs of other groups of disabled people when it comes to sexuality education. This highlights the amount of work which needs to be done around adequate attention to different groups. In our experience, the vast majority of the research also focuses on the education and experiences of disabled *adults*, rather than on the experiences (or lack thereof) of disabled under-18s. This runs the risk of failing to appreciate the importance of supporting the autonomy of disabled children to understand matters such as power dynamics from an early age.

Of course, CRC Article 12 emphasises that children and young people have participation rights, and it has been examined in detail what this means in the case of education (see e.g. Lundy, 2007). In a similar vein in disability studies and practice the ‘nothing about us without us’ approach is prominent, and it is disabled children and young people who should be developing the curriculum, and even delivering it. Guidance should be taken from good practice examples in sexuality education generally, such as in Norway, Sweden, the Netherlands, and elsewhere, where such education is considered consistent with international guidance and based on the premise that under-18s are rights-holders who have an entitlement to information and to enjoy their sexuality (Campbell, 2016).

There is also much work to be done in countering curricula and attitudes which are contrary to the dignity of disabled under-18s. At the same University of Liverpool event, a number of attendees were teachers providing such education. Some outlined how in their experience disabled children (for example those with behaviour issues) were sometimes excluded from mainstream lessons concerning sexuality education on the basis of presumptions that it was not suitable for them, or that they would be disruptive (see European Children’s Rights Unit Briefing, 2018). Such segregation and inferior education for disabled people is presumably in violation of the UK’s Equality Act 2010. For such discussions to move forward, international human rights frameworks (as well as domestic law equality frameworks) must be harnessed. It must be emphasised through discussion, lobbying and litigation (if necessary) that disabled under-18s have a right to sexuality education, and that an insincere ‘vulnerability’ discourse cannot be instrumentalised by state institutions or others for the purpose of shirking responsibilities.

Conclusion

Agency has proven a valuable term in the past few decades for encapsulating the ways in which children contribute to and shape their lives, families and communities. Autonomy, however, is a more suitable term for speaking about children’s rights to make decisions about their own person, whether we are talking about this in the legal context, or in a more rhetorical way. This seems particularly important to recognise when one understands that under-18s have traditionally been excluded from the ‘autonomy’ discourse concerning laws relating to adults around, for example, sex, medical treatment and family life. This exclusion of under-18s from the prioritisation of autonomy in the liberal democracy appears to be based on the assumption that adults’ and children’s worlds, and the experiences inherent in them, are entirely separate (Daly, 2018).

Of course they are not – under-18s sometimes engage in sex, are exposed to sexual abuse, and have views and wishes about matters such as medical treatment and family life. Yet the priority for children’s autonomy – whether within relevant laws or popular discourse – does not exist to any degree similar to that pertaining to adults; instead there is generally a binary approach whereby adults are assumed to be autonomous and under-18s are not. Caution is needed in framing autonomy as simply valuing the liberal individual, however. Autonomy must be understood with an appreciation for our relationships with others, and of the fluid nature of our knowledge and capabilities, in that *failing* to provide support from autonomy may render children vulnerable.

This need to emphasise autonomy, and support for autonomy, is demonstrated well when it comes to sexuality education for disabled under-18s. In dis/ableist cultures, disabled people are routinely denied access to their sexual lives, selves and bodies (Liddiard 2018). They

experience restrictions, both institutional and legal, on their intimate contact (Siebers, 2008: 136). In the context of under-18s, intimate citizenship becomes even more difficult to claim, as disabled under-18s are portrayed as sexless and/or hypersexual. Disabled children and young people may then be excluded from education and other socialisation processes which prepare people for love and sex (Davies 2000: 181). Stigmatising ‘vulnerability’ discourses reinforces dominant expectations of ableist sexual normalcy, and cause anxiety for young disabled people (Liddiard, 2018: 61).

Individualist notions of vulnerability place the onus on the disabled child rather than institutional inequality; inequality which features a failure to consider the diversity of the lives of under-18s, and the diversity of those entitled to sexuality education. Such narratives frequently prevent (accessible) information, and sexual support – as well as the necessary space and access to sexual and intimate life – for disabled people. Paradoxically, then, this may *increase* the sexual vulnerability of disabled under-18s.

Considering the many ways in which under-18s do not fit their mandatory legally incapacitated status prompts us to think about vulnerability. Where under-18s may wish to engage in sexual learning or encounters; where they are themselves parents, for example. Where they engage in behaviours that we do not usually associate with under-18s it becomes clear that the adult/child dichotomy is not so straightforward. It prompts questions as to whether holding adults as entirely responsible, unless they are deemed to entirely lack mental capacity, is sensible; as Herring (2012; 2016) has argued in the context of consent to medical treatment and other matters.

Likewise being compelled to consider what kind of sexuality education is desired, useful and appropriate for disabled under-18s will encourage us to rethink sexuality education itself. It compels us to ask how the content, structure and delivery of sexuality education must be tailored to meet the needs of those who do not fit normative stereotypes. It prompts us to question how it can be delivered without perpetuating and reinforcing inequalities already in existence between adults and children; and between disabled and non-disabled people. It is disabled under-18s themselves who must lead this discussion and lead the design and delivery of sexuality education.

Where systems are *compelled* to accommodate sexuality education and information for disabled under-18s, it will have a positive effect of challenging normative constructions of sexuality. This will educate populations more generally, as it will insist that we think outside the box about what sexual normalcy is, and about what autonomy and vulnerability really mean in this and other contexts.

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