

Becoming intelligible woman: Gender, disability and resistance at the border zone of youth

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Becoming intelligible woman: Gender, disability and resistance at the border zone of youth

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journals.sagepub.com/home/fap**Jen Slater** 

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Abstract

This paper considers young disabled women navigating ableist and heteronormative constructs of adult womanhood. We consider adult womanhood at the embodied intersection of gender, sexuality and dis/ability (categories themselves mediated by race, class, coloniality, etc.). For young disabled women, questions of gender and sexuality were more often than not denied. Gendered and sexual identities were therefore politically and strategically used to claim “adult” and “woman.” Yet, such identities often felt restricted to binary gendered frameworks. Already positioned through ableism as non-normative, to exist outside of heteronormativity felt dangerous, risking paternalism and non-consensual bodily intervention. Drawing on the cases of Ashley X and Marie Adams, we argue that these dangers are often more severe for those with labels of intellectual impairment and/or considered to have the most “severe” impairments. Adulthood needs to be understood, not as a natural state of development (the endpoint of youth), but as a heteronormative and ableist socio-cultural-political construct, as well as a complex site of negotiation, conflict and resistance, which (differently) restricts how young people are able to become in the world. We fill a gap in scholarship by exploring the intersection of critical disability studies, crip theory and youth studies from a feminist perspective.

Keywords

youth, adulthood, disability, queer, crip

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Setting the scene

This paper is framed around a story set on a cold, blustery and wet, February Friday night in Reykjavik, Iceland. The story is of the three authors – all young women¹ then in their early to mid-20s – heading downtown into the nightlife of Iceland's capital city. It was the end of Jen's first week in the country, visiting as a researcher from the UK. Freyja and Embla, both of whom are disabled women and were then working at the Independent Living Centre in Reykjavik (NPA Miðstöðin, 2013), had offered to take Jen out for the evening.² Jen narrates the story:

Embla had kindly agreed to pick me up, so I waved goodbye to my hosts, and dashed out to the car. As I was getting in, Embla told me that Freyja was running late. Freyja still had to do her makeup and, because "she takes *ages* to do her makeup", she'd catch up with us later. I turned and looked at Embla. She was wearing a black dress, leather jacket, heeled boots, face made-up, and hair done. Then I caught a glimpse of myself in the rear-view mirror: make-up-less, hair a mess. I looked down at my straight-out-of-the-case outfit: the usual jeans, my most "Icelandic" woolly jumper, hidden under my technical raincoat. Gloves, hat and snow-boots finish it off nicely. "Mum will be pleased at least; it's very sensible clothing for the Icelandic Winter". I wonder how I'm going to feel with the hipsters of trendy downtown Reykjavik though, and feel a bit downhearted. "You look nice," I say to Embla, "I'm going to feel a right scruff coming out with you two". "Don't worry about it", Embla reassures me, "it's okay for you; you're not disabled. I have to get dressed up; I don't want to live the disability stereotype!". (Story recorded in research diary, 4 February 2012)

Our aim in this paper is not to tell the story of that night out (which continued enjoyably, but fairly unremarkably). Rather, we interrogate the final statement made by Embla, "*it's okay for you; you're not disabled. I have to get dressed up; I don't want to live the disability stereotype!*" We use this statement to frame a wider argument around the ableism and heteronormativity of adult womanhood. As further outlined in the section which follows this introduction, this embodied moment prompts us to ask wider questions about adulthood, womanhood, youth and disability. Namely, we explore what prompts Embla to declare that she, as a disabled young woman, must get dressed up to not live "the disability stereotype." Lesko's (2012) conceptualisation of "youth as border zone," Butler's (1999) ideas of "intelligible subjects," alongside an exploration of ableism (Campbell, 2009; Mingus, 2011), theoretically underpin our work. After outlining how we came to write this paper, two consecutive sections contextualise research surrounding adulthood: first, we introduce how some within disability studies have challenged the disablism within disabled young people's lives; second, we introduce Lesko's understandings of "youth as a border zone." We argue that Lesko's work can productively extend current disability studies perspectives of youth and adulthood. Noting, however, that Lesko omits to discuss disability, theories of ableism,

alongside queer and crip theory, build our theoretical perspective in a section called *Ableist Heteronormativity*.

Through our analysis, we highlight the dangerous ableist heteronormativity of adulthood and womanhood driven by binary gendered, ableist, racialised and classed constructs of independence, financial self-sufficiency, property ownership and normative family relations, including parenthood. Using our own conversations alongside case studies of Ashley X and Marie Adams (Roets, Adams, & Hove, 2006), we explore how the possibilities for resisting normative adulthood constructs differ depending upon intersectional identities and social positioning. In particular, we focus on the implications of adulthood for young disabled women, including those with labels of intellectual impairment who are often particularly excluded from gendered and sexualised discourse. Our overarching argument is that adulthood is not an innate way of being, neither is it wholly age based. Rather, adulthood is an ableist concept, which intersects with identity, embodiment and social positioning, to constrain the ways that all young people can (or cannot) “become-in-the-world-with-others” (Price & Shildrick, 2002, p. 62). The paper adds to this special section by denaturalising “adulthood,” shining a light on who is left out of “adult,” and locates adulthood (or the impossibility of adulthood) at the embodied intersection of gender, sexuality and dis/ability³ (categories in themselves mediated by race, class, coloniality, and so on). More broadly, the paper fills a gap in scholarship exploring the intersection of disability studies, crip theory and studies of youth from a feminist perspective.

How we came to write this paper

The paper uses a mixture of illustrative case study examples, theoretical explorations and conversations between the three authors to argue the dangers of ableist and heteronormative adulthood. We include this section of the paper, on how we came to be writing this together, following Handforth and Taylor (2016), who highlight the value in attempting to make the embodied process of feminist co-writing (at least partially) explicit. We also include this section of the paper as we agree with Richardson (1998) that we have learnt through the process of writing together, and hope that through the inclusion of this section the reader will more readily understand our relationships, positionalities and methodological perspectives.

Conversations between the three authors began as part of an auto/ethnographic (Spry, 2001) study with young disabled people across the UK and Iceland in 2011 and 2012. The aim of the research was to interrogate the meanings associated with “youth,” “adult,” “disabled” and “able” (Slater, 2015). Jen was the researcher, spending three months (between February and April 2012) with Embla, Freyja and other young disabled people in Iceland. Freyja and Embla were participants in Jen’s research, and at the time, they were working in Iceland’s first and only Independent Living Cooperative, which they had together founded in 2010 (NPA Miðstöðin, 2013). Although the research began as an ethnography, Jen followed Spry (2001) in employing the term auto/ethnography to highlight that although the aim of research was not to tell Jen’s story, Jen’s story was significant

and tangled amongst the stories of others (see also Slater, 2015). To name Freyja and Embla only as participants in Jen's research, however, is to downplay their significance in the research process, and to not fully explain the relationships between the three authors. At the time of fieldwork, Freyja was 25, Embla 21, and Jen 23. We spent lots of time "hanging out," meeting almost daily. Jen was welcomed into Embla and Freyja's *saumaklíbbur*,⁴ introduced to their Icelandic friends and comrades and through these connections spent time with disabled children, young people and their parents, as well as with others working or with an interest in disability studies.

When in Iceland, Freyja and Embla became Jen's social as well as research circle. As Jen put it in their research diary, "with every interaction I was thinking again about my 'data', and my relationships with youth, adulthood and disability" (Slater, 2013, p. 134). Since Jen left Iceland, the three authors have remained colleagues and friends – staying in touch online via email and social media, meeting-up for social occasions and at various disability studies events. Although in many ways productive, friendship through and alongside research brought with it particular ethical dilemmas (Ellis & Bochner, 2000; Tillmann-Healy, 2003). Ethical approval was gained through Manchester Metropolitan University's ethics committee, but ethics went much deeper than just "procedural ethics" (Guillemin & Gillam, 2004, p. 263). Jen drew on principles from participatory disability studies research (Chappell, 2000; Priestley & Stone, 1996; Zarb, 1992), feminist methodology (e.g. Macpherson & Fine, 1995) and other projects where friends were participants, or friends had been made through the research process (Ellis & Bochner, 2000; Tillmann-Healy, 2003). Relying heavily on their research diary for both data gathering and analysis (see Richardson, 1998), Jen recorded stories as they saw and heard them. Yet, Jen tried to ensure representations were considered fair by their participants by validating ideas with young disabled people throughout the continuous and iterative process of analysis (Zarb, 1992). This was not to seek any truth or objectivity, but in order to treat stories, and participants, with the respect they deserved. With Embla and Freyja, this included writing a conference paper, *Crip-Queering Adulthood: Three Stories of Growing Up* (Ágústsdóttir, Haraldsdóttir, & Slater, 2013). *Crip-Queering Adulthood* was presented at *The Child, Youth, Family and Disability Conference* held at Manchester Metropolitan University in 2012. This paper is a development of *Crip-Queering Adulthood* and some reflections from within *Crip-Queering Adulthood* are used as "data." More details of the research which originally took place, including further theorisations, can be found in Slater (2015). We turn now to introduce our theoretical perspectives.

Contextualising adulthood: Critiques from disability studies

The vignette in the introduction tells the story of three young women going downtown on a Friday night in Reykjavik. It describes a moment where Jen, as a non-disabled, queer, white, non-binary young woman, feels awkward for not dressing in a conventionally feminine way in comparison to her disabled friends, Embla and Freyja. Embla's response is for Jen not to worry about it, "you're not disabled. I

don't want to live the disability stereotype." In this section, we begin our interrogations of this moment, by using "youth" to shine a critical light on "adulthood."

Human development is often understood through biologically essentialist viewpoints as a relatively predictable series of stages: from child, through youth, we reach adulthood, before old-age and death. Whereas adulthood is presented as a time of relative stability (Wyn & White, 1997), youth is often considered a life-stage characterised by "turbulence," "trouble" (Finn, 2001), "storm and stress" (G. S. Hall, 1904). This discourse of youth as unstable is perpetuated through particular disciplinary perspectives, such as psychology, neurology and medicine (Ortega & Choudhury, 2011), self-help guides that (shakily) rest upon these disciplines (e.g. Bradley, 2003; for critique, see Elman, 2014; Slater, 2016), as well as policy, practice (Finn, 2001) and popular discourse (Elman, 2014; Slater, 2016). As the instability of youth must be overcome to reach the security of adulthood, through youth, questions of adulthood futures emerge, often based around future paid work, heterosexual relationships and parenting (Slater, 2015). Yet, the questions that are asked (or indeed, not asked) vary dependent upon identity, embodiment and social positioning. As Freyja explains, reflecting on her experiences as a disabled young woman:

At family gatherings I felt the worst. My cousins who were similar ages to me were asked by relatives about their future plans: whether they had a boyfriend, if they were going overseas, and what they were planning on doing after college. I wasn't asked a thing. Even nowadays when my cousins are cross-questioned about their relationship statuses or when they are going to have children, I get the embarrassing gaze: "I will not make her uncomfortable by asking her about her love life or future plans of children, she obviously doesn't have a boyfriend...and kids?! Well..." The one time a distant relative *did* ask me if I was seeing someone and what plans I had after graduation I was so astonished I almost fell out of my chair...but it felt good, being cross-questioned, just this once. (Ágústsðóttir et al., 2013)

Reflecting Freyja's experiences, disability studies researchers (Beresford, 2004; Hughes, Russell, & Paterson, 2005; Morris, 2002) have highlighted that disabled young people are rarely expected to fulfil normative adulthood expectations by, for example, having (heterosexual) relationships, going overseas or to college, or having children (see also Appleby, 1992). Disabled young people are therefore often denied the questions commonly asked to their non-disabled peers. In reaction, some authors have argued that disabled young people are "just the same as everybody else." Morris (2002, p. 7), for example, writes that "sex and sexuality figure as important issues in the transition to adulthood for non-disabled young people but adults do not always recognise that disabled young people will have the same sexual feelings of others of their age."

It is perhaps thanks to an argument that disabled people are "just like everybody else" that there has been a degree of liberal acceptance of *some* disabled people into the various markers of adulthood (sexuality, independence, financial self-sufficiency) (Slater, 2015). Yet, pondering over their disabled son who "over the years has

collected a variety of labels,” Ferguson and Ferguson (2001, p. 71) worry that a discourse of disabled people as “just like everybody else” continues to exclude those disabled people positioned furthest from the markers of adulthood, particularly those with labels of intellectual impairment. Furthermore, Sothorn (2007, p. 151) highlights that a discourse of disabled people are “just the same as everybody else” relies on “reinforcing the binary construction of gender through which disabled bodies (and others) become Othered.” Sothorn uses the example of (hetero)sexuality, arguing that although some disabled people’s sexuality may have been acknowledged, a reliance on “sameness” often functions within a heterosexual framework (Abbott, 2013; Iino, 2011; Sothorn, 2007). The problems of this were clear for Embla, as a disabled lesbian: “. . . just for the record, when you’re gay, you’re never asked if you’ll have kids. With disability comes desexualisation . . . so not being straight never comes into the equation. Disabled lesbians . . . is there such a thing?” (Ágústsðóttir et al., 2013).

The final question Embla asks: “disabled lesbians . . . is there such a thing?” refers to research done by Skjaldardóttir (2012), a friend of Embla and Freyja. When doing research into society’s attitudes towards disabled lesbians for her BA thesis, Skjaldardóttir was not surprised to find that there was little support for disabled lesbians in Iceland. She was, however, shocked at the response of many of her friends when she told them the subject of her research: “disabled lesbians . . . is there such a thing?” It seemed the desexualisation of disabled women meant that the possibility of disabled lesbians was unimaginable.

Contextualising adulthood: Youth as a border zone

Although not focusing specifically on disability, Lesko (2012) takes a different approach to examining youth and adulthood. Rather than beginning with young people’s experiences, she instead interrogates and historically contextualises youth as a social construct. For Lesko, questions of adulthood futures are not separate or peripheral to our understandings of youth, but integral to them. Youth, Lesko (2002) argues, is not a “natural” stage of child–adult development, but a policed “border zone” between child and adult which is produced as a social fact. Disciplining technologies such as schools, families and youth services work differently to shape the incomplete, irrational, unproductive, desexualised child, into the complete, rational, productive, and (hetero)sexual, adult, particular to a time and place. Youth as border zone is unlike traditional developmental approaches which equate “developmental difference” as innate and often deficient (particularly where disabled people are concerned), yet neither is it equitable with more liberal approaches which emerge from some disability research and activism, which argue through a discourse of “sameness.” Rather, youth as border zone allows us to see such difference as relational: entwined betwixt and between infinite possible forms of embodiment and the socio-cultural-political context within which that embodiment functions and is understood.

To contextualise her argument, Lesko (2012) highlights that the concept of adolescence was first acknowledged at a time of American colonisation at the

turn of the twentieth century. Although projected as “objective” and “neutral,” therefore, the adult citizen desired by psychologists studying adolescence was both raced (white) and gendered (with the majority of study concentrating on boys). Technologies of adolescence rationalised boys’ education which aimed “to produce young, masculine, Christians” (Lesko, 2002, p. 183) who would work for the good of the nation. Policies and practices worked in particular racialised and gendered ways. There was a general consensus, for example, that educators needed to create “more manly boys and more womanly girls” (Lesko, 2012, p. 66). One way of doing this was to encourage boys to take part in team sports. However, as team work was considered to be “a form of association rooted in the heritage of the Anglo-Saxon ‘race’” (Lesko, 2012, p. 67), it was thought that team sport would “come naturally to Anglo-Saxon youth but could uplift others if they were educated to it” (Lesko, 2012, p. 66). In other words, team play was considered as a way to make non-Anglo-Saxon boys “more manly,” and with this were connotations of being “more white.” Girls, on the other hand, were encouraged to take part in more “appropriately feminine” activities, such as cheerleading. This gendered focus reified the binary between young men and women, and worked to further establish a heteronormative order.

Notwithstanding Lesko’s (2012) productive analysis, disability is not addressed in her work. The absence of a disability analysis is particularly conspicuous as “ability” is implicated within the racialised and heteronormative discourses of adulthood to which young people are expected to aspire. Lesko highlights, for example, the importance put on “youth” during its emergence as a time to create a “healthy” generation of young adults to make up a physically productive workforce who would be able to fight for their country. To be able and adult was also to be white and male (Lesko, 2002). The paper now turns, therefore, to further Lesko’s work by centring ableism in our exploration of adulthood.

Ableist heteronormativity

According to Campbell (2009, p. 4) ableism is 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.” Disablism, on the other hand, is the resultant practices which lead to the oppression of disabled people. Much disability studies research around disabled young people rightly highlights the disablism practices in the lives of young disabled people (Goodley, 2014). Many young disabled people, for example, do not have the opportunity for a night downtown, whether that is due to a lack of finances (more disabled people than non-disabled live in poverty, and living with impairment is often expensive – Tinson, Aldridge, Born, & Hughes, 2016), necessary support (as highlighted by the Stay Up Late campaign: <http://stayuplate.org/>), inaccessible venues or discriminatory practices (e.g. Bullen, 2016). Rather than considering specific disablism practices taking place within youth or adulthood, however, in this paper we are considering the ableist heteronormativity of adulthood constructs and how this restricts the possibilities of becoming for young disabled women at

the border zone of youth. We argue that the ableism of adulthood means that disabled people are rarely understood as “adult” and thus disablist practice is normalised. We see the ableism of adulthood, for example, when we take into account Lesko’s (2002) analysis of the desired “healthy” generation of adults at the turn of the twentieth century. We can also point to present-day examples, such as the ableist requirement to be a flexible neoliberal worker in adulthood (the expectation that a “good” worker should be able to spontaneously work long, unpredictable hours and travel seamlessly).

Considering adulthood through a lens of ableism, however, also highlights how adulthood functions in relation to other forms of social positioning (gender, class, race, sexuality and so on). Campbell (2012, p. 12) points out that the corporeal (adult) standard is not only reliant on the category of dis/ability, rather “[t]he nuances of ableism [...] are transcategorical, having specific cultural alignments with other factors such as race, gender, sexuality and coloniality” (see also Mingus, 2011). Although to be considered “adult” is to be considered “able” – “able” to be financially self-sufficient, “able” to be independent, “able” to fulfil the projected needs of a particular society at a given time (currently, global capitalism) – the particular expectations of “ability” are also gendered, racialised, and so on. Butler (1999, p. xxii), for example, asks us to consider “how presumptions about normative gender and sexuality determine in advance what will qualify as ‘human’ and the ‘livable’. For Butler rather than something “natural,” sex and gender are acts materialised through performativity. Gender is presented to us as a binary male/female construct and heterosexual hegemony is (re)constituted through a reiterative performance of these roles. For a life to be considered “liveable,” one must be considered an intelligible subject by “becoming gendered in conformity with recognizable standards of gender intelligibility” (Butler, 1999, p. 22). Normative adulthood therefore relies upon “correct” performances of gender.

McRuer (2006a, 2006b) furthers Butler’s work. He argues that understandings of the “able body” are entwined with constructs of normative genders and sexualities. Just as Butler claims the heterosexual ideal to be performative, McRuer argues that the ideal able-bodied identity can never fully be achieved. He also highlights that disabled people are rarely considered to be normatively gendered or sexual (see also Gill, 2015). Rather, they are often understood as queer: never fully able to achieve heterosexuality, and always understood (paradoxically) as either asexual or hypersexual (see also Liddiard, 2014). In some ways, this seems to juxtapose Embla’s experiences as a disabled lesbian. Yet, here McRuer uses queer in the sense of transgression and resistance from the norm, rather than in relation to a specific identity. Furthermore, he highlights that queer people have also been implicated in narratives of disability through, for example, medicalisation and searches for a “cure” to non-normative genders and sexualities (McRuer, 2006a, p. 94).

Un/intelligible womanhood

To centre ableism in a discussion of adulthood is to think holistically and intersectionally (Crenshaw, 1989) about who is/is not understood as “able”/“adult,”

and how adulthood constructs and prioritises certain ways of being in the world (white, male, non-disabled, heterosexual, cisgender, living in Western Europe or North America). For young disabled women, dangerous relationships between disability, youth, gender and sexuality function to posit their bodies as desexualised (Garland-Thomson, 2002), childlike (Johnson, Walmsley, & Wolfe, 2010), and therefore the property of others, to be subject to intervention (Barton, 1993; McCarthy, 1998). We had many conversations around the entwined workings of ableism and gender performativity, whilst Jen was in Iceland. Wrapped up in these were always performances of “adult” and “able.” As we saw in the opening vignette, Embla and Freyja felt that Jen’s “able-bodied” privilege allowed Jen to resist an expected performance of heterofemininity in a way that they, as disabled young women, could not. Indeed, there was no initial expectation of heterofemininity there for young disabled women to resist. Therefore, whilst Jen could make a decision to not put on make-up and get dressed up on a night out, Embla and Freyja took the political decision to assert themselves as gendered and sexual beings through a performance of femme. Taking the “not bothering” option would (as Embla puts it) mean “living the stereotype of the cute little disabled girl”; the desexualised disabled person, positioned in a perpetually childlike state (Garland-Thomson, 2002). Yet, although the decision was indeed a conscious politicisation to assert disability in the realms of womanhood (something which we return to in the penultimate section), it required constant self-surveillance.

Embla and Freyja’s situation illustrates Sothorn’s (2007) worry around a normalisation approach to disabled people’s genders and sexualities. Sothorn (2007, p. 147) argues that in (neo)liberal societies, rather than see an explicit segregation and overt intolerability of difference, we see instead a “liberal intolerability of difference,” which manifests itself in different ways. In order to be rendered “knowable,” both queer sexualities and the disabled body have to be rendered “normal.” Once “normal,” they are accepted within a certain “knowable,” “normal” frameworks which “puts pressure on disabled bodies to be sexualised in hegemonically knowable ways” (Sothorn, 2007, p. 152). To be intelligible as adult, disabled young people must “pass” as intelligible by buying into the strict gender binaries of the heterosexual matrix (Butler, 1999). Although “passing” within this framework has its own problems, the danger for those unable to pass is that they remain outside this knowable subjectivity, remaining other, and therefore subhuman. This is particularly pertinent for those that may never be considered as “the same as everybody else” (Ferguson & Ferguson, 2001; Kittay, 1999; Goodley & Runswick-Cole, 2016) or within normative constructs of gender and sexuality (Gill, 2015), such as some people with labels of intellectual impairment.

Intellectual impairment and intersectionality

We turn now to use case studies of two young women with intellectual impairments, Ashley X and Marie Adams, to illustrate how ableist, heteronormative discourses of adulthood can lead to non-consensual bodily intervention for disabled young women. The stories of these young women starkly illustrate

the dangers of not being considered an adult woman that provoked Embla's statement ("it's okay for you; you're not disabled. I have to get dressed up; I don't want to live the disability stereotype!"). As we cannot separate disability, gender and sexuality from classed and raced understandings of adulthood, in the final part of this section we explicitly address how class and race also mediate understandings of normative womanhood and adulthood.

Ashley X was nine-years-old when, in 2007, news broke that she had three years earlier been subject to medical intervention to stop her growth and "development." Treatment included hysterectomy, the removal of breast buds, to prohibit growth of her breasts, and high doses of oestrogen to stop growth (Edwards, 2008). Much of the justification around Ashley's treatment depended on her presumed inability to communicate and to rationalise decisions about her own future (Kafer, 2013). As Ashley was not understood as (becoming) rational and reasonable, neither was she understood as becoming adult (Kittay & Carlson, 2010; Slater, 2015). Ashley's doctors defended their actions by situating Ashley's life in contrast to adulthood constructs associated with productivity (i.e. that she would not work or have a romantic relationship) (Kafer, 2013). Yet, there were also specificities relating to Ashley's sexed (female) and gendered (girl) status. Ashley's parents and medical professionals decided on her behalf that ensuring Ashley's body never acquired breasts or menstruated would prevent her future discomfort, and make it easier for her parents to take care of her (K. Q. Hall, 2011). The treatment and subsequent discussion explicitly marked Ashley's reproductive capabilities as markers of womanhood, and therefore to Ashley (never to be considered as a woman) as redundant.

As headlines broke, Ashley's parents were criticised. It was posed that their actions were "grotesque" (cited in K. Q. Hall, 2011, p.5), to which they replied: "the prospect of having a full-grown fertile woman endowed with the mind of a baby is what is really grotesque" (cited in K. Q. Hall, 2011, p. 5). Ashley's sterilisation was deemed a way of preventing the "embodied asynchrony" (Kafer, 2013, p. 48) of a mind and body considered to be developing at different speeds from each other. The adult female body was framed as fundamentally about reproduction, and as Ashley's life was not intelligible as an adult woman, the treatment was considered by medics as justifiable. Ashley's corporeality disrupted understandings of child and adult, and therefore interventions were made for her body to remain in a state that could easily be understood as childlike.

For Kafer (2013, p. 56), therefore, Ashley's treatment was positioned "as a cure for adult womanhood as much as adult disability." Kafer also highlights how the Ashley X case functioned around a dangerous and slippery discourse of severity of impairment. Ashley's treatment was based on the premise that she was innately different to her peers, and Kafer (2013, p. 67) highlights that even others within disability scholarship and activism have positioned Ashley as "too severely disabled to be considered a disabled person."

Without denying the problematic nature of justifying bodily intervention dependent upon "severity of impairment," it would be wrong to presume that sterilisation was only ever enforced on those with the most "severe impairments."

Parents of children with impairments considered less “severe” contacted Ashley’s parents after the treatment became public to share their enthusiasm that it be possible for their child (Kafer, 2013). In another example, Roets et al. (2006) tell a story of one of the authors, Marie Adams, who has the label of intellectual impairment. They document the battles that Marie and her allies faced when sterilisation was, in 2002, “imposed on Marie as an absolute, ineluctable necessity” (p. 167). In this story, we see disability linked with non-normative sexuality and a childlike state of being. Declared “sexually unfit,” Marie is also deemed incapable of making other decisions that we may associate with adulthood, such as controlling her own finances. The article explains that there was no attempt to engage Marie in informed discussions of sex and sexuality. Rather, attempts are made to scare her into agreeing to sterilisation as she is given the advice that “by going ahead with the sterilization she was never going to have trouble with ‘shady blokes who want to rape you’ any more” (Roets et al., 2006, p. 170).

With support from her self-advocacy group, mother and academic advocates, Marie resisted sterilisation. However, the sterilisation of disabled young women with labels of intellectual impairment is not a historical phenomenon (Roets et al., 2006). Marie’s fight took place in Belgium in 2002. Furthermore, although the occurrence of surgical sterilisation may have decreased, young women with labels of intellectual impairment are often given long-term contraception, without explanation, their knowledge or consent (Chamberlain, Rauh, Passer, McGrath, & Burket, 1984; McCarthy, 1998; Tilley, Walmsley, Earle, & Atkinson, 2012). The justification often used is that sterilisation/long-term contraception prevents abuse (McCarthy, 1998) – an argument that Kafer (2013) points out is hinted at within the Ashley X case. Such arguments, however, not only remove blame from violent perpetrators and place responsibility upon women, but increase the likelihood of abuse, as much abuse is perpetrated by male family and staff members, who presumably realise their persecution is reduced as detection through pregnancy will not occur (McCarthy, 1998, p. 571).

Our argument so far is that the ableism and heteronormativity of adulthood restricts how young disabled women can live their gendered and sexual lives. For young disabled women, particularly those with labels of intellectual impairment, being understood outside of normative constructs of womanhood can be dangerous. Furthermore, as the label of intellectual impairment is in itself socially constructed within societies which value certain ways of being over others, the benchmarks for who is/is not considered “intellectually impaired” and therefore “adult” are slippery. Writing in a US context, Erevles (1996), for example, highlights that young people of colour are more likely to be given a label of “developmental delay” than their white peers. Speaking in the UK, McWade (2016) highlights that people who are economically and socially disadvantaged are most likely to be detained under the Mental Health Act, and therefore deemed irrational and outside understandings of “adult.” Indeed, it is within the last 25 years at the time of writing that the World Health Association removed (male) homosexuality as a mental health problem from the International Classification of Diseases (ICD), and gender dysphoria (a label that transgender people often need to acquire

to access healthcare) continues to be classified as a “disorder” (for critical discussions see Tosh, 2014).

Questioning the essentialism of such labels is important as it further separates markers of adulthood (and indeed womanhood) from innate ways of being, and instead positions them as a product of unequal societies. Furthermore, it highlights the relevance of classed and racialised perspectives to those of gender, sex, sexuality and disability. In her analysis of Ashley X, Kafer reminds us that Ashley’s whiteness and middle class status mean that she is a child who can spark public discourse, as she is deemed worthy of concern and “care” (even if the results of this “care” are dubious). Similarly, Embla, Freyja and Jen are all white and none of us is poor. Ndopu (2013), who describes himself as “a Black Queer Crip of the African diaspora,” explains that when wearing trendy, fashionable clothes he is read differently than when wearing casual clothes. As he puts it, “casual attire [. . .] render[s] my body the personification of dishevelment and neglect,” not only due to the associations of disability with charity, but the intersectional workings of this perception of charity with gender, sexuality, class and race. Although the way we present ourselves can be a conscious act of resistance, this resistance is functioning within larger systemic constraints which deem our bodies a locus of social control (Ndopu, 2013).

Resistance: Crip-queering adulthood

With the above complexities in mind, we nevertheless want to end with a more positive, and perhaps more subversive, account of our trip downtown. For both Butler (1999) and McRuer (2006a), considering gender and/or dis/ability as performative also reveals space to subvert these normative gender roles; and they both make the importance of this clear as simply recognising discourses of gender and dis/ability as socially and culturally constituted will not necessarily lead to their undoing (Butler, 1993; McRuer, 2006a). They therefore ask us to “work to the weakness in the norm” (McRuer, 2006b, p. 30). For Butler (1993), this means being “critically queer”; and for McRuer (2006b), it means being “severely disabled”: using the inevitable failure to live up to the heterosexual/able-bodied “ideal” as a way of mobilising.

In our story of the trip downtown, we see resistance emerging differently dependent on perceptions of dis/ability. On the one hand, Jen’s “dressing down” and Embla’s “dressing up” could be presumed to be acting in opposition to, and perhaps un-doing the work of one another. Whilst Jen’s dressing down may challenge some expectations of young women’s bodies, Embla strives to be accepted within this construct. One reading of the story could therefore be that we are challenging each other’s political projects. Yet, McRuer (2006a, 2006b) argues that like the heterosexual ideal, the performativity of ability has been normalised, naturalised, to the extent that it goes unnoticed. The normative expectation on Jen as a young non-disabled woman is to perform heterofemininity. A performance of this heterofemininity, however, would not emerge as an utterance, but a silence. In failing to perform heterofemininity, however, attention is brought to Jen’s embodiment in a way that “dressing up” may not have done. Embla’s non-normative embodiment, on the other hand, becomes a spectacle (Shildrick, 1997). As we have seen, for disabled

young women, the expectation is not to cross into normative adulthood by meeting gendered and sexual norms, but to remain the genderless, desexualised eternal child. By failing to perform “ability,” Embla inevitably fails in a performance of heterosexuality. Therefore, it is through a performance of femme that her embodiment acts as resistance. To follow, McRuer, however, Embla not only stands as a challenge to the discourse of disabled people as genderless and desexualised but also a queering/cripping of gender norms.

Conclusion

In this paper, we have argued that adulthood is a social construct, based on ableist and heteronormative ideals. This has consequences for all young people in attempting to cross the border zone of youth. Yet, we have addressed the specific consequences for disabled young women. Whereas for many young people, the transition between youth and adulthood comes with expectation of (hetero)sexual coupling, work and family prospects, disabled young women are rarely understood within normative constructs of gender, sexuality and adulthood, and are therefore denied such expectation. This can be dangerous: leading to paternalism and, in some cases, non-consensual bodily intervention.

We have also argued, however, that the solution is not simply to argue young disabled women into normative constructs of adulthood gender and sexuality. There are several reasons for this. First, even if some young disabled women are accepted within normative constructs, for other young disabled women acceptance within normativity seems unlikely. This is particularly the case for those with labels of intellectual impairments or considered to have the most “severe” impairments. Second, ableist adulthood expectation is shrouded in other forms of harmful normativity, which is reinforced, rather than critiqued, through an argument of “sameness.” In this paper, we have concentrated on heterosexual expectation, which cannot be separated from binary constructs of gender. Arguing disabled young women into heteronormative expectation further marginalises – and even renders unintelligible – queer disabled people.

Finally, reinforcing normativity restricts the ways that young disabled people are able to resist the ableism and heteronormativity of adulthood. As we saw in the story of heading downtown, playing with gender, or simply resting from the undeniable activism of being disabled and femme, did not feel like an option for Embla and Freyja. The paper has also demonstrated, therefore, the complexities and nuances of active resistance to adulthood normativity. We call, therefore, for careful readings and interrogations of adulthood which pay attention to how the intersections of gender, sexuality, disability, race, class and global positioning, mediate how adulthood – and indeed a resistance to adulthood – can play out.

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Notes

1. In the period between the fieldwork taking place, drafts of this paper, and final publication, Jen has questioned their relationship with “woman” and now identifies as a trans genderqueer person. Jen now uses singular they/them pronouns. However, we have left woman in here to recognise Jen’s past relationship with woman and the fluidity of gender more broadly. We have, however, used they/them pronouns in relation to Jen.
2. This story has also been told and differently analysed in Slater (2015) and Liddiard and Slater (2017). This paper, however, offers the fullest analysis.
3. When we use dis/ability (with a forward slash) we are acknowledging the co-constituted relationship between “ability” and “disability” – troubling the binary, yet hierarchical, relationship between the two (the prioritisation of “ability”), and highlighting that both are terms constructed by unequal societies which, through ableism and disablism, prioritise certain ways of being and doing (the terms ableism and disablism are further explored in the section called *Ableist Heteronormativity*) (Goodley, 2014). When we use the term disability (without a forward slash), we are following the social model definition of disability, referring to a marginalised and politicised group of people who are disabled by society.
4. Translating to “sewing club,” *saumaklúbbur* is a time where Icelandic women traditionally get together to sew, although nowadays sewing rarely takes place; instead women eat, drink and chat together.

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References

- Abbott, D. (2013). Nudge, nudge, wink, wink: Love, sex and gay men with intellectual disabilities – A helping hand or a human right? *Journal of Intellectual Disability Research*, 57(11), 1079–1087.
- Appleby, Y. (1992). Disability and ‘compulsory heterosexuality’. *Feminism & Psychology*, 2(3), 502–505.
- Ágústs dóttir, E., Haraldsdóttir, F., & Slater, J. (2013). Crip-queering adulthood: Three stories of growing up. Paper presented at Child, Youth, Family and Disability Conference. Manchester Metropolitan University, Manchester, UK.
- Barton, L. (1993). The struggle for citizenship: The case of disabled people. *Disability & Society*, 8(3), 235–248.
- Beresford, B. (2004). On the road to nowhere? Young disabled people and transition. *Child: Care, Health and Development*, 30(6), 581–587.
- Bradley, M. J. (2003). *Yes, your teen is crazy!: Loving your kid without losing your mind*. Gig Harbor, WA: Harbor Press.
- Bullen, J. (2016, September 8). ‘I felt humiliated,’ disabled student denied entry to Dalston nightclub over safety fears. *The Evening Standard*. Retrieved from <http://www.standard.co.uk/news/london/disabled-student-denied-entry-to-dalston-nightclub-over-safety-fears-a3340571.html>.

- Butler, J. (1993). *Bodies that matter: On the discursive limits of "sex."* London: Routledge.
- Butler, J. (1999). *Gender trouble: Feminism and the subversion of identity* (10th Anniversary ed.). New York, NY: Routledge.
- Campbell, F. K. (2009). *Contours of ableism: The production of disability and abledness.* Basingstoke, UK: Palgrave Macmillan.
- Campbell, F. K. (2012). Stalking ableism: Using disability to expose 'abled' narcissism. In: D. Goodley, B. Hughes, & L. Davis (Eds.), *Disability and social theory: New approaches and directions* (pp. 212–230). Basingstoke, UK: Palgrave Macmillan.
- Chamberlain, A., Rauh, J., Passer, A., McGrath, M., & Burket, R. (1984). Issues in fertility control for mentally retarded female adolescents: I. Sexual activity, sexual abuse, and contraception. *Pediatrics*, 73(4), 445–450.
- Chappell, A. (2000). Emergence of participatory methodology in learning difficulty research: Understanding the context. *British Journal of Learning Disabilities*, 28(1), 38–43.
- Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *The University of Chicago Legal Forum*, 8, 139–167.
- Edwards, S. D. (2008). The Ashley treatment: A step too far, or not far enough? *Journal of Medical Ethics*, 34(5), 341–343.
- Ellis, C., & Bochner, A. P. (2000). Autoethnography, personal narrative, reflexivity. In: N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 733–768). London, UK: SAGE.
- Elman, J. P. (2014). *Chronic youth: Disability, sexuality, and U.S. media cultures of rehabilitation.* New York: New York University Press.
- Erevelles, N. (1996). Disability and the dialectics of difference. *Disability & Society*, 11(4), 519–538.
- Ferguson, P. M., & Ferguson, D. L. (2001). Winks, blinks, squints and twitches: Looking for disability, culture and self-determination through our son's left eye. *Scandinavian Journal of Disability Research*, 3(2), 71–90.
- Finn, J. L. (2001). Text and turbulence: Representing adolescence as pathology in the human services. *Childhood*, 8(2), 167–191.
- Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. *NWSA Journal*, 14(3), 1–32.
- Gill, M. (2015). *Already doing it: Intellectual disability and sexual agency.* Minneapolis, MN: University of Minnesota Press.
- Goodley, D. (2014). *Dis/ability Studies: Theorising disablism and ableism.* New York, NY: Routledge.
- Goodley, D., & Runswick-Cole, K. (2016). Becoming dishuman: Thinking about the human through dis/ability. *Discourse: Studies in the Cultural Politics of Education*, 37(1), 1–15.
- Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "Ethically Important Moments" in research. *Qualitative Inquiry*, 10(2), 261–280.
- Hall, G. S. (1904). *Adolescence: Its psychology and its relation to physiology, anthropology, sociology, sex, crime, religion and education* (Vols. 1 and 2). New York, NY: Appleton.
- Hall, K. Q. (2011). Reimagining disability and gender through feminist studies: An introduction. In: K. Q. Hall (Ed.), *Feminist disability studies* (pp. 1–10). Bloomington: Indiana University Press.
- Handforth, R., & Taylor, C. A. (2016). Doing academic writing differently: A feminist bricolage. *Gender and Education*, 28(5), 627–643.

- Hughes, B., Russell, R., & Paterson, K. (2005). Nothing to be had 'off the peg': Consumption, identity and the immobilization of young disabled people. *Disability & Society*, 20(1), 3–17.
- Iino, Y. (2011). VI. On disabled access to the sexual realm: How does a feminist perspective contribute? *Feminism & Psychology*, 21(4), 536–541.
- Johnson, K., Walmsley, J., & Wolfe, M. (2010). *People with intellectual disabilities: Towards a good life?* Bristol, UK: Policy Press.
- Kafer, A. (2013). *Feminist, queer, crip*. Bloomington: Indiana University Press.
- Kittay, E. F. (1999). *Love's labor: Essays on women, equality, and dependency*. New York, NY: Routledge.
- Kittay, E. F., & Carlson, L. (Eds.). (2010). *Cognitive disability and its challenge to moral philosophy*. Oxford, UK: Wiley-Blackwell.
- Lesko, N. (2002). Making adolescence at the turn of the century: Discourse and the exclusion of girls. *Current Issues in Comparative Education*, 2(2), 182–190.
- Lesko, N. (2012). *Act your age: A cultural construction of adolescence* (2nd ed.). New York, NY: Routledge.
- Liddiard, K. (2014). The work of disabled identities in intimate relationships. *Disability & Society*, 29(1), 115–128.
- Liddiard, K., & Slater, J. (2017). 'Like, pissing yourself is not a particularly attractive quality, let's be honest': Learning to contain through youth, adulthood and disability. *Sexualities*, 21(3), 319–333.
- Macpherson, P., & Fine, M. (1995). Hungry for an us: Adolescent girls and adult women negotiating territories of race, gender, class and difference. *Feminism & Psychology*, 5(2), 181–200.
- McCarthy, M. (1998). Whose body is it anyway? Pressures and control for women with learning disabilities. *Disability & Society*, 13(4), 557–574.
- McRuer, R. (2006a). Compulsory able-bodiedness and queer/disabled existence. In: L. J. Davis (Ed.), *The disability studies reader* (pp. 369–381). New York, NY: Routledge.
- McRuer, R. (2006b). *Crip theory*. New York: New York University Press.
- McWade, B. (2016). Recovery-as-policy as a form of neoliberal state making. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Policy and Practice*, 5(3), 62–81.
- Mingus, M. (2011, August 22). Moving toward the ugly: A politic beyond desirability. Retrieved from <http://leavingevidence.wordpress.com/2011/08/22/moving-toward-the-ugly-a-politic-beyond-desirability/>.
- Morris, J. (2002). *Young disabled people moving into adulthood foundations: Analysis informing change*. York, UK: Joseph Rowntree Foundation.
- Ndopu, E. (2013). A black crip's perspective on fashion and embodied resistance. Retrieved from <http://thefeministwire.com/2013/02/a-black-crips-perspective-on-fashion-and-embodied-resistance/>.
- NPA Miðstöðin. (2013). NPA Miðstöðin. Retrieved from <http://www.npa.is/>.
- Ortega, F., & Choudhury, S. (2011). 'Wired up differently': Autism, adolescence and the politics of neurological identities. *Subjectivity*, 4(3), 323–345.
- Price, J., & Shildrick, M. (2002). Bodies together: Touch, ethics and disability. In: M. Corker, & T. Shakespeare (Eds.), *Disability/postmodernity: Embodying disability theory* (pp. 63–75). New York: Continuum.
- Priestley, M., & Stone, E. (1996). Parasites, pawns and partners: Disability research and the role of non-disabled researchers. *British Journal of Sociology*, 47(4), 699–716.
- Richardson, L. (1998). Writing: A method of inquiry. In: N. K. Denzin, & Y. S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (pp. 345–372). London, UK: SAGE.

- Roets, G., Adams, M., & Hove, G. V. (2006). Challenging the monologue about silent sterilization: Implications for self-advocacy. *British Journal of Learning Disabilities*, 34(3), 167–174.
- Schildrick, M. (1997). *Leaky bodies and boundaries: Feminism, postmodernism and (bio)ethics*. New York, NY: Routledge.
- Skjaldardóttir, S. S. (2012, February 17). Fötludh lesbía, er Það til? [Disabled lesbians, is there such a thing?]. Retrieved from <http://www.innihald.is/index.php/thjodfelagsmal/mannrettindi/item/754-foetludh-lesbia-er-thadh-til>.
- Slater, J. (2013). *Constructions, perceptions and expectations of being youth: A critical disability perspective*. PhD thesis. Research Institute of Health and Social Change, Manchester Metropolitan University, Manchester, UK.
- Slater, J. (2015). *Youth and disability: A challenge to Mr Reasonable*. Farnham, UK: Ashgate.
- Slater, J. (2016). The (normal) non-normativity of youth. In: R. Mallett, C. Ogden, & J. Slater (Eds.), *Theorising normalcy and the mundane: Precarious positions* (pp. 14–144). Chester, UK: University of Chester Press.
- Sothern, M. (2007). You could truly be yourself if you just weren't you: Sexuality, disabled body space, and the (neo) liberal politics of self-help. *Environment and Planning D: Society and Space*, 25(1), 144–159.
- Spry, T. (2001). Performing autoethnography: An embodied methodological praxis. *Qualitative Inquiry*, 7(6), 706–732.
- Tilley, E., Walmsley, J., Earle, S., & Atkinson, D. (2012). 'The silence is roaring': Sterilization, reproductive rights and women with intellectual disabilities. *Disability & Society*, 27(3), 413–426.
- Tillmann-Healy, L. M. (2003). Friendship as method. *Qualitative Inquiry*, 9(5), 729–749.
- Tinson, A., Aldridge, H., Born, T. B., & Hughes, C. (2016). *Disability and poverty: Why disability must be at the centre of poverty reduction*. London, UK: New Policy Institute.
- Tosh, J. (2014). *Perverse psychology: The pathologization of sexual violence and transgenderism*. New York, NY: Routledge.
- Wyn, J., & White, R. (1997). *Rethinking youth*. London, UK: SAGE.
- Zarb, G. (1992). On the road to Damascus: First steps towards changing the relations of disability research production. *Disability & Society*, 7(2), 125–138.

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