

Disability and sexuality: Desires and pleasures

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Abstract

There is an ongoing missing discourse of pleasure in studies of sexuality and disability, and considerations of sexual pleasures and sexual desire in the lives of people with disabilities play very little part in public discourse. This opening article analyzes some of the major theoretical influences and debates informing prevailing assumptions about disability and sexuality. An exposition of the theoretical and conceptual terrains that underpin and shape this special issue works to canvas a series of often disparate sites of contestation, and suggests that disabled and sexual embodied subjectivities are much more than ‘asexual’ or ‘hypersexual’ pathological constructions. The articles explore the ways in which the intersection of disability and sexuality involves an understanding of the interlocking discourses of normality, sexuality, able-bodiedness, heteronormativity and desire, which can shape possibilities for sex, sexuality, pleasure and intimacy for people with a disability. What will become evident is that a greater attention to the phenomenology of sexual embodiment, pleasure, desire, and the diverse meanings of intimacy and the erotic, can make significant contributions to social and scholarly analyses of disability and sexuality. The utilization of different methodological approaches that can attend to complexity and diversity in the experience of sex and sexuality further constitutes part of the critique of ableist narratives of the ‘normal’ desiring and desirable subject that cannot account for the intersubjective conditions in which embodied subjectivity is constructed and pleasure experienced.

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Introduction

With the commencement of the National Disability Insurance Scheme (NDIS) in Australia in 2013 there have been calls for sexual assistance to be included in the lists of services offered to Australians with a disability (Yau, 2013: 1). Citing Scandinavian countries that have adopted the Nordic Model of laws aimed at enhancing the individual autonomy and self-determination of people with disabilities,¹ sex therapist Matthew Yau, for instance, argues that Australia should make provisions for people with disabilities to access government-funded sex therapy, sexual education and sexual services. 'Disability will not dampen one's sexual and intimacy needs', writes Yau, and most people 'disabled or not, have a basic need to be loved and intimate, as well as express love and affection' (2013: 2). While Yau is not dismissive of the positive experiences of individuals with disabilities that identify as asexual, or the idea that pleasure may be derived from different forms of sensuality and intimacy, his argument is important to an analysis of disability and sexuality. This is because it highlights an intersection between dominant understandings of 'embodiment' and sexuality where there is a presumed assumption that people with disabilities are always already asexual – an assumption that further relies on impressions of disabled people as inevitably undesiring and undesirable (see also Kim, 2011: 479).

In 2014, SBS News (Australia) aired the short documentary 'I have cerebral palsy and I enjoy having sex'. This documentary focuses on the life of 60-year-old Colin who has cerebral palsy and regularly sees a sex worker called Rachel. Narrated by both Colin and Rachel, the documentary tells the story of Colin's previous experience of never having had the opportunity to talk about, or experience sex, which he relates partially to his family upbringing where 'sex wasn't talked about', a lack of opportunity, and a lack of privacy. Colin's access to sexual intimacy was at first at the discretion of staff who helped him access sex workers despite an organizational policy that prohibited staff from assisting access to sexual services. Colin then moved into another house that put him in touch with an advocacy organization in Sydney that connects people with disabilities to sex workers. It was here that he met Rachel with whom he has ongoing contact.

The two socio-cultural events described above focus attention on a major issue that continues to circulate within the realm of conceptualizing disability and sexuality; an anxiety about the inclusion of desire as a productive force in many socio-political and cultural discourses of sex and sexuality for people with disabilities. The inclusion of desire as a productive force in these discourses is significant, however, because it can serve to empower people with disabilities as 'sexual agents, entitled to pleasure and therefore responsible for their own sexuality' (Tepper, 2000: 283; see also Fine, 1988). Yet opportunities for sexual agency,

self-determination and autonomy have been marred by essentialist and essentializing discourses that equate disabled sexualities as Other to, and of, the ‘normal’ heterosexual able-body. The socio-pathologization of disabled bodies as abnormal Other and functional deficit has further led, particularly in the West, to render these bodies hypervisible (and hypersexual) or, by contrast, invisible (and nonsexual) in both lay consciousness and the social everyday. It appears that to construct new ways of seeing and hearing subjects of disability and sexuality as desiring and desirable beings, there is a need to shift the gaze of the mainstream beyond the hierarchical double-bind of one and its ‘Other’, where one can only be ‘one’ or abject ‘Other’.

This special issue, focused on disability and sexuality, desires and pleasures, necessarily invites reflection about the state of the field as we examine the knowledge that has been produced on disability and sexuality identifying theoretical and methodological orthodoxies, trajectories, limitations and connections. This task will not only take us back over the recent history of scholarship on disability and sexuality but also take us forward – mapping a future for a rich, nuanced and socially-just literature on the subject. The following sections trace the problems of understanding sexuality and disability in extant literature and identify some of the key conceptual, theoretical and methodological terrains to be considered in the practice of researching and analyzing disability, sexuality, pleasure and desiring subjectivities. It explores the ways that the intersection of disability and sexuality involves an understanding of the interlocking discourses of normality, sexuality, able-bodiedness, heteronormativity and desire, which further allows for a comprehension of some of the limits and possibilities for sexuality, pleasure and desire that discursively and materially impact upon people with a disability. What will become evident is that a greater attention to the phenomenology of sexual embodiment, pleasure, desire, and the diverse meanings of intimacy and the erotic can make significant contributions to social and scholarly analyses of disability and sexuality. Theoretical and conceptual attention to the coalescence of disability and sexuality in scholarly theorizing, and the diversity and complexity of subjectivities, has further implications for thinking about methods and methodology, which is addressed in the final section of the article.

Mapping the terrain: Theorizing sexuality and disability, desires and pleasures

Essentialism and dichotomous thinking

There is an extant literature that identifies the ways that the disabled body and the sexual body have each been constituted in the context of a long and powerful effort to construct the ‘normal’ body (e.g. Butler, 1990, 1993; Campbell, 2009; Davis, 1995, 1997, 2002; Fuss, 1991; Gatens, 1996; Grosz, 1994; Petersen, 1998; Shilling, 1993). Constructions of this ‘normal’ body have historically invoked binary notions of a ‘healthy’ self and the medically diseased or disabled ‘other’, drawn over other

binary assumptions about gender, class, 'race' and sexuality. Campbell (2009) and Seymour (1998), for instance, claim that biological essentialism has been used as a powerful ideological weapon, constructing dominant ideologies of gender, sexuality and disability subsequently used to legitimate relations of inequality in other areas of social life. Foucault (1994) writes that biological and medical discourses share an analysis of the body that perceives it as the pre-social, biological basis on which the superstructure and of the self and society are founded.

In this special issue, both the diversity and complexity of disability and sexuality are emphasized without recourse to essentialist terms where both identity and the body are considered wholly biologically constructed. Overboe (1999) contends that, when theorizing disability and sexuality, there must be recognition that the embodied self materializes in discourse and through the lived, living and sensuous body (see also Loeser, 2014; Loeser and Crowley, 2006). Foucault (1988: 5) also maintains that it is through the intersubjective demands of relationships that individuals 'discover, in desire, the truth of their being, be it natural or fallen'. Identity materializes in response to an embodied engagement and connection with the environment, both social and concrete.

In refuting Cartesian logics of dichotomous thinking that posit the biological as always already divorced from the discursive and ideological, bodies and identities are understood in this issue as materialities that gain meaning through various modes of symbolic representation and material practice in the lived everyday. The issue further refutes logics of dichotomous thinking that divide the identities of male from female, self from other, abled from disabled, normal from abnormal. The Cartesian tradition (see Butler, 1990, 1993; Davis, 1995, 1997; Fuss, 1991; Gatens, 1996; Grosz, 1994; Petersen, 1998; Shilling, 1993) has been more influential than any other tradition in defining particular bodies as sources of interference in, and danger to, the operations of political reason and the will to truth. The constitution of those bodies classified as dangerous is inversely related to the image of a homogeneous political body that is implicitly male. Grosz (1994) maintains that the historical construal of the male body as 'bounded' and therefore 'normal' in Western societies is central to the legitimation of certain strategies of violence and oppression against those bodies deemed as dangerous 'Others', such as the female body and the disabled body.

The inherent 'dangerousness' affiliated with disability is further reflected in those social and cultural analyses that continue to occlude, or barely mention, the issue of disability. In 1995, Davis (1995: 5) wrote that the 'disabled body is a nightmare for the fashionable discourse of theory because that discourse has been limited by the very predilection of the dominant, ableist culture. The body is seen as a site of *jouissance*, a native ground of pleasure, a scene of excess that defies reason', leaving the disabled body at the margins of the margins (see also Meekosha and Shuttleworth, 2009). In relation to this, the question of how and in what ways the disabled body can be desired and desiring, a site of sensuality and pleasure that facilitates a corporeal sense of (a)sexual being-in-the-world, has remained largely unaddressed. Crowley (2012) claims that we are never outside dangerous terrain in the arena of disability, and the very utterance of the term disability heralds a

theoretical, conceptual and experiential storm. The storm is not diminished when we attend to and immerse ourselves further into the worlds of queer disability – a disparate world that brings the deep unevenness of the mundane, the celebratory and the perversities of sex and sexualities to an Other.

Queering disability and sexuality

Any study of disability and sexuality is buttressed against a series of problematics that are inextricably located in specificity as well as the generalities of certain embodiments and psy-worlds (psychology, psychiatry). The asylum has housed as neighbours the disabled and the queer with the sexuality of both presented as a threat to society and in need of containment.² Both disabled and queer peoples have been subject to practices of forced sterilization, and both were subject to overtly eugenic excesses such as badging and extermination during the Nazi regime as they were identified as ‘deviant’, ‘perverse’ and ‘undesirable’. While such practices are relatively uncommon in the contemporary West, there persists a widely held idea that to have ‘a severe disability precludes both functional sex, and sexual pleasure and desire’ (Tremain, 2000: 57), and that to be queer and disabled is to be denied the possibility of having a sexuality that is socially intelligible. As McRuer and Wilkerson (2003: 8) write:

To have a sexuality that is socially intelligible, much less legitimated, one must meet, along with heteronormativity, the norm of physical and mental ability, and one way to deny intelligibility and legitimacy is to insist that an identity or practice is unseemly and must be kept private.

Carrie Sandhal (2003) has further highlighted the ways that the assumption of disabled people as always already asexual has led to processes of desexualization, including denial of access to sexual assistance, contraception and sexual education, and a lack of access to opportunities for sexual engagement in institutional settings. These processes further manifest in the material conditions of disabled people’s lives where economic discrimination and exclusion can reduce and deplete opportunities for sex, intimacy and love, and where their living conditions deny space for autonomy, agency and adulthood (Liddiard, 2014). ‘While the diagnostic gaze aimed at queer bodies ferrets out symptoms of a “diseased sexuality”, the diagnostic gaze aimed at disabled bodies tends to negate sexuality’ (Sandhal, 2003: 46). In these ways, desexualization is an active and ongoing process imposed by society in the names of ‘protection’ and ‘risk management’ so that the sexual orientations and desires of people with disabilities are made irrelevant.

The past two decades have seen marked scholarly shifts in the ways we ‘experience’ disability and queer, with debates importantly still raging about the salience of the forms of theorization, issues of abstractedness and the absence of voice. This is layered with contestation about the significance of embodied accounts and the

need to see, hear, touch, smell and taste subjugated knowledges, the experiences and stories of those whose lives contest and confront the normative whether they are classified or self-named as 'disabled', 'crip', queer, gay, lesbian, trans, intersex and the manifestations of further and emerging sexual identities. For Shelley Tremain (2000), a sufficient account for the sexualities and identities of disabled queers requires a recognition of non-normative sexual practices and a revision of essentialist conceptions of sex and gender.

The contributions of queer theory to the analysis of sexuality and disability are crucial due to a recognition of the diversity of both heterosexualities and non-heterosexualities and the histories of violence against those bodies and identities considered 'non-normative' – which has historically included people with disabilities. As opposed to considering disability and sexuality as distinct and opposing categories, a queer approach provokes an 'ontology of connectedness between and a crossing of temporalities and cultures' (Parisi, 2009: 98) where attention is drawn to the inextricable mixing of identities as involution and becoming. Within this framework, disability and sexuality is 'becoming' and becoming more, as a language and a practice, a materiality to open and not to curtail. This point is reinforced in Shildrick's 'Queering performativity: Disability after Deleuze' (2004). For Shildrick, the study of disability and sexuality necessarily involves an explicated concern with 'the notion of human flourishing' and the 'plasticity of sexuality' (2004: 1). There is an attention to both the discursive and the material that are both replete with complexity: what is it, for example, to have cerebral palsy and to have a communication board that has minimal language for even straight and vanilla relationships, let alone queer and trans-performative, and where one does not want to be the fetish object of non-normative heterosexual or BDSM sexuality (see Sellwood, 2015)?

The significance of a queer approach also works in its capacity to dramatize the incoherencies in the allegedly stable relations between chromosomal sex, gender and sexual desire. Judith Butler's (1990) notion of the performative has been used extensively in queer analyses of gender, sexuality and, more recently, queer disabled sexualities. According to Butler, 'there is no gender identity behind the expressions of gender' (p. 25). Acts, gestures and enactments 'are *performative* in the sense that the essence of identity that they otherwise purport to express are *fabrications* manufactured through corporeal signs and other discursive means' (p. 136, emphasis in original). For Butler, the term performative 'suggests a dramatic and contingent construction of meaning' (p. 139). She writes: 'gender proves to be performative...constituting the identity it is purported to be...by the very "expressions" that are said to be its results'. Identity is thus not innate and pre-given, but is a condition of 'doing' (p. 25).

The term performative disturbs the reality of an internal gender core, and reveals the borders around gender as permeable to re-signification and re-invention. The benefit of such a conceptualization of gender is that it disrupts the 'sex = gender = desire' equation, through a focus on those 'identificatory and practical crossings' (Butler, 1991: 17) that de-naturalize and de-stabilize the fixity of sex-gender identity. Butler is clear that 'the very notions of an essential sex and a true

or abiding masculinity or femininity are... part of the strategy that conceals gender's performative character and the performative possibilities for proliferating gender configurations' (p. 141).

This issue also draws on an understanding of the identities of disability and sexuality as active terms. Attention is drawn to the ways that these identities emerge, and are experienced, within 'a systematics of performance' (Uebel, 1997: 5). Since identity materializes in response to an embodied engagement and connection with the environment, it must also be recognized that the social environment is structured by ideologies and rules that prescribe what are 'appropriate' and 'inappropriate' acts, practices and behaviours in particular sites and spaces:

... the way in which the subject constitutes himself [sic] in an active fashion... these practices are nevertheless not something that the individual invents by himself. They are patterns that he finds in his culture and which are proposed, suggested and imposed on him by his culture, his society and his social group. (Foucault, 1988: 11)

It is the circulation of power within the social realm that prompts the cultivation of identity through performances enacted in the presence of others. And it is power as not simply repression but possibility that works to induce pleasures, form knowledges and produce discourses that always already exceed the restricted economy of identity as always fixed, self-same and ahistorical (Foucault, 2001: 120). The possibilities offered through embodied exchanges and engagement in the world intensify the ruptures of meaning encompassed in the production and materialization of subjectivity. This signals an understanding of the body and subjectivity as exceeding hierarchical control and ordering.

The difficulty with Butler's notion of the performative for analyzing disability and sexuality, desires and pleasures, is that it lacks an exploration of the affective mechanisms by which subjects might act collectively to dis/figure gendered and disabled identities. We agree with Lloyd's (1997) criticism when she writes that Butler's emphasis on the individuated subject as it parodies gender does not take into account to whom, or with whom, or for whom, sensual, sensory and reciprocal bodies perform their identities. This criticism has been directed at other queer analyses of disability, sexuality and desire that still beg for 'experience', the narrative of the coal-face, the telling of spit and bodily fluids, sweat and desire, hunger and satiation. Queer-informed analyses have been critiqued for closing the question of the material, sensual and sensate relationship between self and other in the constitution of embodied identity: 'Queer theory... although it purports to examine issues such as embodied desire and performance, often theorizes the body via abstractions of postmodernism, eliding the immediacy and diversity of lived bodily experiences' (Wilkerson and McRuer, 2001: 483).

While a queer deconstruction of the male/female, feminine/masculine, heterosexual/homosexual, impairment/disability dualisms seems crucial in shifting scholarly attention away from the essential 'naturalness' of these categories, it seems that any move that abandons the categories of disability, gender and sexuality is also

itself problematic. As Rosemarie Garland-Thomson (1997: 23) writes, ‘the theoretical bind is that deconstructing oppressive categories can neutralize the effects of real differences.’ The existence of material bodily differences must be ‘claimed, not cast as lack’. An engagement with the multiplicities of embodied difference in the analysis of disability and sexuality requires that scholars avoid the temptation, in the words of Gatens (1996: 27), to ‘replace *one* body with *two*, one ethic with two, one reason with two’ (emphases in original). The reconstruction and repetition of hierarchical binary oppositions implicit in simply adding more ‘universals’ would merely serve to reproduce existing universalist models that do not listen for the voices, desires and experiences of all that fall ‘outside’ their distinctive parameters – such as disabled, female, queer, gay, transgender, bisexual, intersex, lesbian and genderqueer bodies, and bodies of diverse racial and ethnic backgrounds.

Becomings

The recent Deleuzian turn to understanding the non-discursive materiality of bodies as multiple and rhizomatic has drawn attention to the ways that living bodies take up and lay down space and time in their continuous movement of becoming while also, following Crowley (2012: 139), ‘withstand[ing] the territorial tug that is affirmed everywhere through binaries and normalisation’. In the context of disability, sexuality, desires and pleasures, there is a need to listen for the ways that identities and bodies always have connections to other ‘things’ whether other bodies, technologies, identities and spatio-temporal locations. Desire should be heard as a productive, sensual and sensuous force. There is a need to embrace a theoretical and conceptual approach that can hear the chaos of spillage – in all its literal and metaphorical iterations. This special issue pays attention to and embraces the multiplicity, diversity and ‘messiness’ involved in the cultivation and experience of sexuality by people with disabilities. Attention to the multiple intersections and conjunctions of bodies and identities within the intersubjective realm of the wider environment works to belie hierarchical organization and categorical distinctions. It implies an understanding of the disabled and sexual body as a realm of affectivity and a site of multiple struggles that is ambiguously positioned in the production of unexpected and unpredictable connections and linkages to other bodies and identities.

As will be seen in each of the articles in this issue, it is important to recognize the different ways that all identities are marked by the play of difference and obey ‘the logic of more-than-one’ (Hall, 2000[1996]: 17). Those unities proclaimed through identities such as disability, sexuality, as well as race, ethnicity and age, are conceptualized as temporary points of attachment created by discursive practices. In this way, the theoretical and conceptual approach to analyzing disability and sexuality in this issue is consistent with a queer approach, as well as cultural theorist Stuart Hall’s (2000[1996]: 18, 19) conceptualization of identity:

Identities are, as it were, the positions which the subject is obliged to take up while always ‘knowing’ ...that they are representations, that representation is always

constructed across a lack, across a division, from the place of the other, and thus can never be adequate.

This special edition takes up this ‘inadequate’, indeterminate state of movement to allow for both the ‘other’ and for ‘more’ in the analysis of identities. Yet this is about lived reality and not just representation. The explicit significance of the scholarly validation of the lived experiences of disabled bodies lies in their ability to write new stories about disability, as well as recover traditional ones. The recognition and validation of the phenomenological lived and sensuous experiences of disabled embodiment can ‘allow for able-bodied and disabled narratives to be read across and against each other’ (Overboe, 1999: 26). Moreover, a focus on experience works further to disrupt any attempt to lump together various disabling conditions into a single fixed category. Following Shildrick (2007: 54), ‘there are very significant differences between having restricted mobility, and being deaf or sight impaired, or having an intellectual disability . . . different disabilities will impact on sexuality in different ways.’ Disability and sexuality are experienced differently by different people across time, space, place and context.

This special issue identifies and analyzes those expansive desires and possibilities of embodiment that lie beyond the limits imposed by heteronormative ideologies. It takes seriously the arguments by disability scholars that there is an ongoing ‘missing discourse of pleasure’ (Tepper, 2000: 283) in studies of sexuality and disability and that ‘considerations of sexual pleasures and sexual desire in the lives of people with disabilities play very little part in public discourse’ (Shildrick, 2007: 53; see also Rainey, 2011). The theoretical and conceptual treatment of disability, sexuality and embodiment in this issue subsequently draws on different research methodologies that can hear disabled and sexual subjectivity, not as a fixed essence waiting to be ‘discovered’, but rather as an ongoing experiential process of differentiation that is relentless in repetition, while being subject to redefinition, transformation and exchange. Each undertakes a pragmatic interrogation of the intersubjective conditions in which embodied subjectivity is constructed. It is to the issue of methodology that we now turn. This attention to methodological frameworks that can listen for the multiplicities and complexities in the experience of sex and sexuality by people with disabilities simultaneously forms part of the broader critique of universalist models and their heteronormative ableist narratives of the ‘normal’ desiring and desirable sexual body.

Methods and methodologies

A critical reading of the contributions to this special issue through a methodological prism, and thus informed by methodological debates in contemporary critical disability studies and sexuality studies, brings to the fore three key methodological issues which we hope will inflect the trajectory of future work on the subject. First, while the contributors cite the importance of intersectional theory to their research, questions of the methodological complexities of studying multiple and intersecting identities are not discussed. In advancing knowledge

about how sexualities and disabilities coalesce to produce (in)equality we thus need to address what appears to be an ongoing disjuncture between sophisticated theoretical frameworks which recognize subjectivities as plural, multiple and shifting, and our methodological approaches which suggest that identities can be separated for discrete analysis and discussion.

To do so we may learn from feminist researchers who have begun documenting the methodological challenges which emerge from an intersectional perspective so that we attend to the full messiness of identity formation and not erroneously prioritize, conflate or overlook particular markers of social difference (e.g. Bryant and Pini, 2011). This is particularly urgent given that, as both Davis (1995) and Meekosha and Shuttleworth (2009: 62) rightly argue, the 'conventional mantra' of difference invoked in the academy has excluded disability. In this work some have advocated that intersectionality is best addressed through particular methods. Valentine (2007: 15), for example, argues for the efficacy of the case study as a means to demonstrate the ways in which 'gender, sexuality, class, motherhood and the cultural/linguistic identity "Deaf" become salient/disappear, are claimed/rejected and are made relevant/irrelevant' in the life of one woman. Alternatively, Rogers (2009: 286) presents a strong case for the value of autoethnographic storytelling as a method to illuminate the 'difficulty, difference, and the social processes that come with the lived experience' of disability and sexuality.

In a key contribution to methodological debates about intersectionality, Ludvig (2006: 247) asks: '*Who defines when, where, which and why* particular differences are given recognition while others are not?' (emphases in original). It is a question which gestures towards a second theme we suggest should guide further work on disability and sexuality. That is, the need for reflexive interrogation of issues relating to positionality, representation and voice in research. Such a call, is, of course, not new. Indeed, the critique of 'disabling methodologies' and the adoption of counter research processes and practices which address issues of power, ethics and social change has been well established in critical disability studies (Goodley, 1999). This has necessarily spilled over into the more specific critical disability scholarship on sexuality.

Thus, alongside calls for further scholarship on disability and sexuality, writers in the field have typically counselled to 'listen to disabled people themselves talking about their sexual desires and experiences' (Shakespeare et al., 1996: 7) and advised to 'take seriously what disabled people themselves actually do and say' in relation to sexuality (Shuttleworth, 2004: 56). Against the long history of methodological reflexivity in critical disability studies, efforts in sexuality studies have been more recent as Browne and Nash (2010) editorialize in introducing their collection *Queer Methods and Methodologies*. At the same time the types of ruminations around knowledge production that have been introduced to sexuality studies offer useful entry points for advancing methodologies in critical disability studies. We may benefit, for example, by taking a queer lens to ethics committees and thus subvert and challenge the fact that protocols are embedded in normative labelling and categorization of people with a disability as unquestionably and unilaterally

'vulnerable' (see Gustafson and Brunger, 2014). Alternatively we may queer notions of empowerment in critical disability studies thereby critiquing and unsettling the relationship between researcher and participant and opening up new spaces for dialogue and action (see Chappell et al., 2014). Finally, we may queer what constitutes research, recalibrating it beyond its traditionally narrow definitions so that it encompasses sharing, friendship and collaboration (see Ho, 2013).

'Listening to disabled people themselves talking about their sexual desires and experiences' involves further attuning ourselves to the diversity of ways people may experience pleasure and intimacy that is not necessarily genital-centric. Simpson (2012: 99) writes that 'part of the institutionalized repression of the body includes restricting the domain of sexuality itself so that it becomes genito-centric'. Restrictive notions of sexuality serve to desexualize the rest of the body. Genital-oriented notions of sexuality can also serve to limit the lexicon of words by which people can describe their experiences of sexual pleasure (Jackson, 1999). Liddiard's (2013) research with men with a spinal cord injury, for example, shows that many of the participants found it very difficult to describe their embodied experiences of pleasure because they did not 'ejaculate', 'climax' or 'orgasm' and could not make use of these terms. Many of the articles in this issue demonstrate the ways that sex, sexuality, desire and pleasure for people with disabilities can be experienced in and across multiple zones of the body, resulting in different understandings and knowings of what sex and intimacy 'is' and 'can be' in different spaces and contexts. There is a clear need for creative methodologies and methods that can help articulate and envisage more fluid, open sexual desires, practices and pleasures beyond heteronormative genito-centric thought. Attention to stories of sensation, effect and affect in research on disability, sex and sexuality can therefore contribute to the lexicons of pleasure through which people may describe their sexual lives.

A third and related methodological issue we noted as we considered the contributions to this special issue, and broader methodological themes in the literature pertaining to sexuality and disability, concerns choice of method. All the published articles utilize qualitative approaches. While this is tied to the epistemological base from which contributions have emerged, such as cultural and/or feminist studies, it belies recent attempts by activist scholars to argue that emancipatory research is not, and should not, be associated with a particular methodological approach, and that reflexive approaches to survey design and analysis can address the types of criticisms of the method levelled against it by researchers focused on social justice (e.g. Browne, 2010; Hughes and Cohen, 2010; Kwan and Schwanen, 2009). Beyond the dominance of qualitative approaches is a further concentration on textual analysis as a method within the qualitative tradition. This is no doubt a reflection of the pervasiveness of the media in 21st-century life and the associated rise of visual culture and new social media across the globe. As is evident from the range and scope of the textual data that contributors to this special issue have utilized, which includes film, poetry, online discussion forums and newspaper reports, meanings, norms and practices associated with disability and sexuality are now circulated widely via a vast array of media. They may still be merely a footnote in

the broader 'media-zation of sexualities' (Plummer, 2008: 10) but they are nevertheless deserving of attention.

At the same time we question whether the preponderance of textual-based studies is an indication of the difficulties of undertaking field-based research on the subject of disability and sexuality. Negotiating ethics committees, accessing a research site, establishing and building relationships with participants and leaving the field can all be vexed in research about the intersections between disability and sexuality. Moreover, all require a significant commitment of time, which, in the current climate of neoliberal managerialism is highly circumscribed in universities. Innovative and creative approaches to methods are evident in both critical disability studies and in sexuality studies as separate fields of inquiry. Methodological toolkits include diaries, photographs, online storytelling platforms, dyadic interviewing, creative writing and drawing (e.g. Allen, 2011; Caldwell, 2013; Sunderland et al., 2015). We thus have much to learn from each other in bringing the two areas of study into a more sustained and vigorous conversation.

Concluding remarks

This article has sought to provide an exposition of the theoretical and conceptual terrains that underpin and shape this special issue of *Sexualities*. The theoretical and conceptual framework for analyzing disability and sexuality, desires and pleasures draws on a variety of resources. This is because, as Shildrick (2007) has recognized, disability encompasses enormous variations and no one universal ideology can hear and see the complexities and diversities of disabled sexualities and desiring subjectivities, and the multiple modes through which they are both represented and lived. Drawing on various elements of feminist, queer, poststructuralist, phenomenological and Deleuzian thought, and selected strands from critical disability studies, gender studies and cultural studies, the articles in this issue work in different ways to critique conventional essentialist discourses of disability and sexuality by allowing bodies and selves to be heard as unfinished materialities, produced amid competing truths that are created in and over time, place, space, geography, and culture.

An interdisciplinary theoretical and conceptual framework is useful for problematizing both normative assumptions of identity built on internal fixity, linearity and self-presence, and understandings of disability and sexuality that obscure the sensory, affective and the sensual in the ongoing cultivation of identity. It works to bring to the fore those expansive desires and possibilities of embodiment that lie beyond the limits imposed by a heteronormative universalist model where all bodies are deemed as fixed, and the sexualities of people with disabilities are always already deemed 'abnormal Other'. Desire is rethought not in terms of deficiency and lack, but as a productive force in terms that do not necessarily centre on 'genital sexuality, or on the goal of self-completion in sexual satisfaction' (Shildrick, 2004). The theoretical and conceptual framing has necessary implications for thinking about methods and methodologies for researching disability and sexuality, desires and pleasures. There is a need for methodology that is reflexive

and which can illuminate the messiness of identity formation and subjectivity as plural, multiple and shifting.

The combination and establishment of the theoretical, conceptual and methodological framing of this issue enables a move beyond a description of experiences of ‘disability’ and ‘sexuality’ to navigable strategies, communicative practices and sites of ambivalence, ambiguity and contradiction – issues elided through non-fluid universalist constructions of disability, sexuality and the body. The articles that constitute the next two sections of this special issue hear through an admixture of embodied senses and the creative corporeal capacities of people with disabilities to offer other plains of telling.

Notes

1. Sex surrogacy for people with disabilities also operates in the UK, Belgium and the USA.
2. Liddiard and Slater’s article in this special issue of *Sexualities* explores the stories of young people with disabilities as they perform, enact and realize ‘containment’ in the context of youth, gender, disability, crip sex/uality and pleasure.

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