

**Impairment, socialization and embodiment: The sexual oppression of people with physical disabilities**

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## **Abstract**

People with disabilities face multiple forms of social exclusion, discrimination and oppression, including in the domain of sex and sexuality. From a critical psychoanalytic viewpoint, social responses to persons with impairments are strongly unconsciously mediated, and often dominated by projections based on archaic anxieties about dependency, vulnerability and shame. Where disability meets sexuality, these defences may be more prominent still, resulting, for one example, in the prejudiced myth that people with disabilities are disinterested in, or not capable of, sex. Using this theoretical stance, this paper examines how the developmental role of family and societal influences on the social constructions of sexuality and disability are internalized, resisted and negotiated by two South Africans with physical disabilities. Data is drawn from interview material elicited via photovoice methodology. The interview narratives and photographic images are used to explore how sexual oppression may be internalised, creating intra-psychic barriers to inclusion for this already structurally disadvantaged group.

It is well established that, around the world, people with disabilities experience systemic social exclusion and discrimination, often leading to low educational attainment, and high rates of unemployment and poverty (WHO, 2011). While powerful structural barriers to equity are of immense importance, less recognised are the familial, cultural and social beliefs and prohibitions which surround the lives of this minority group. One area of the personal lives of persons with disabilities which is associated with stereotyping, silence and exclusion, is sexuality (Kulick & Rydstrom, 2015; Shakespeare, 2000). This may be due to general misconceptions and stigma attached to disability, as well as specific myths attached to the sexuality of people with disabilities. Examples of the latter are often framed by a split, which sees people with disabilities as either asexual, or hypersexual and perverse (Siebers, 2012).

In this paper, we draw on material from two individual case studies, which formed part of a larger photovoice research project exploring and challenging myths to do with the sexuality of South Africans living with physical disability. The material is interpreted using ideas from critical psychoanalysis, which has become an important branch of the discipline of disability studies over the past two decades (e.g. Goodley, 2011; Marks, 1999; Watermeyer, 2013). As we shall see, the extraordinary evocativeness of the ‘damaged body’ means that socio-political relations around disability are significantly mediated by the projection of archaic, unconscious phantasy. Add sex to this mix, and it should be no surprise that the sexual participation of people with disabilities is contested terrain. The issue of how such projections are internalised, enacted, warded off or endured by their recipients is a central question we pose, aiming to contribute to the dismantling of exclusion and prejudice in this most important area of our shared humanness.

To prepare for consideration of the case material, we move now to look at some of the meaning systems of how ‘disability’ is understood, which form the backdrop against which people with disabilities live their private lives. A discussion of relevant psychoanalytic ideas on disability oppression follows, allowing for a critical analysis of the participants’ discourse.

### **A Psychosocial understanding of disability**

There are many different ways of understanding disability, ranging from the spiritual (disability as a curse) to the biological (disability as biological impairment). Reinforced by the biomedical model of health care practice, disability is typically figured in the popular imagination as a tragedy. Lives of persons with disabilities, consequently, tend to be

represented in one-dimensional ways, involving tropes of loss, damage and invalidity. Alongside disability as a medical or biological tragedy, in many cultures (historical and contemporary), disability is understood as a form of moral tragedy – a divine punishment for sin or a failure of faith, or some form of evil (Goodley, 2011).

In contemporary societies, the medical model of disability has tended to dominate much of our thinking about disability. From this perspective, disability is understood as resulting from an underlying biological, physical or psychological impairment, disorder or disease (Goodley, 2011; Shakespeare, 2014). Within this model, disability is perceived as located *within* the individual – they are disabled because they have an impairment – while denying the structural, cultural and social exclusion which keeps this group in a marginal, disadvantaged position. Prejudiced, demeaning ideas about the human potential of persons with disabilities remain hegemonic in most contexts, and must somehow be overcome, in both outer and inner worlds, in order for flourishing to be possible. Pity, patronisation, avoidance or outright hostility are common responses from a social world which has viewed people with disability as ‘other’, and which through a global legacy of segregation and institutionalisation, has sought to keep disabled people at a distance.

The mid-1970s saw the first emergence of an alternative, politicised view, the so-called ‘social model of disability’ (Oliver, 1986, 1990; Swain et al., 1993). This approach turned attention away from medical diagnoses, reframing the essence of disability as the social injustice of lost opportunities to participate endured by people with impairments, in societies designed exclusively for the needs of the ‘non-disabled’ majority. The social model has been hugely influential in progressing the human rights of people with disabilities (Shakespeare, 2014), although global progress towards disability equity, many would agree, has been disappointing (Grech & Soldatic, 2016; Watermeyer, 2013). The focus of the social model, is on tangible, material ‘barriers to participation’. The political current it fostered was one in which intra-psychic, personal and embodied experiences of disability were marginalised (Marks, 1999; Morris, 1989; Thomas, 1999). Indeed, there was immense resistance within the social model-oriented ‘mainstream’ of the disability studies discipline to performing research in these areas, believing that it would promote stereotypes of vulnerability and pathology (e.g. Finkelstein, 1996). During the 1990s, criticism from feminist disability studies scholars grew, objecting to the ‘arid materialism’ of the social model view, and its view that oppression only took place in the public domain. The social model promoted a denial of the

fact that life in the face of discrimination and demeaning treatment left lasting impressions on the inner lives of people with disabilities, as such experiences would on anyone. In addition, the social model of disability provided no theoretical basis to make sense of embodied experiences such as functional limitation, pain and fatigue, which are part of the interaction between individual and context which produces disadvantage. Some critics within the social model (e.g. French, 1993; Shakespeare, 2014), however, argued for the need to consider the realities of impairment and embodied experience and social exclusion. Lastly, the social model had nothing to say about how disability-based inequality is created and maintained at interpersonal and intra-psychic levels, through familial and intimate relationships, and every other aspect of socialisation.

It was the omissions outlined above, the social model's macro-level focus on social constructions of disability, and the need to understand at a more micro-level the developmental interaction between embodied, psychological and social experiences, that critical psychoanalytic thought began to address, beginning with the work of Sinason (1992) and Marks (1999).

Marks (1999) and Watermeyer (2009; 2013) developed a psychoanalytically informed model of disability inequality, based mainly on Kleinian concepts such as splitting, projection, projective identification and paranoid-schizoid functioning. At the heart of this view is the idea that disability has become culturally attached to unconscious existential anxieties to do with corporeal vulnerability, shame and mortality which we all share. Unconscious fears to do with dependency, the acceptability of one's body, intellectual and physical adequacy, shunning and isolation, among much else, are readily evoked by images of disability, thanks to media representations and cultural mores. People with visible disabilities, consequently, are compelled to live in the face of a gale of projections, as, in fantasy, the personifications of all that narcissistic culture (Lasch, 1984) seeks to disavow (Shakespeare, 1994). Members of this minority are at times idealised as inspirational 'supercrips', but more often psychically relegated to a human junk-heap of damaged goods. Social transacting around disability is, thus, often influenced by paranoid-schizoid functioning, recreating individuals with disabilities as the personifications of fantasy, and hence silencing the subjective experience of oppression, along with most other parts of what are, in fact, complex human lives like any others. In this sense, people with disabilities represent a specific, amplified case of psychic scapegoating, in which neoliberal society deals with narcissistic wounds of dependency,

helplessness and vulnerability by locating these in a reviled group, who are then perceived as weak and unfit (Layton, 2014). Through social organisation which deprives the disability community in tangible ways, its members are created as receptacles for projective identification, corralled into marginal lives which facilitate an enactment of the split-off abjection of the majority (Watermeyer & Swartz, 2016).

Although psychoanalysis has, until this work from disability studies, been notably silent on disability, a small literature is scattered over the mid- to late twentieth century. It has been harshly criticised (Asch & Rousso, 1985; Harris & Wideman, 1988; Watermeyer, 2013), for promoting a view of disability which is, in effect, essentialist. In other words, since this work ignores the context of oppressive social relationships in which disability occurs, it in effect posits causal links between bodily difference and psychological disorder (Watermeyer, 2002). In short, the nature of the ‘damaged’ body itself, rather than the nature of social responses to it, is employed as the primary locus of attribution for the catalogue of psychopathology that the view ascribes to people living with disability. The links between psychological disorder and homosexuality were viewed in much the same way, as inherent to homosexuality itself, rather than the consequences of oppressive social response to non-heterosexuality (Rohleder, forthcoming). This is relevant to our discussion, since such a view carries the, frankly, indefensible implication that experiences of embodiment are pre-social, probably demonstrating how analysts, too, are mesmerised by disability. To all of us, the body is compelling; bodily difference captures our attention, cathexis and projection follow, and fantasies seem real. If this essentialist view of the relationship between body and psyche were true, it would imply that the sexuality of people with disabilities, as a part of embodied experience generally, would inevitably be disturbed, abject, or dead. But developing children with disabilities do not experience their differently functioning bodies against the backdrop of some inherent ‘normate’ (Garland-Thomson, 1997) model of functioning which positions their embodied experiences as divergent. Instead –

The body which the congenitally impaired infant possesses is the only body which he or she has ever experienced; its boundaries and shape, its motility and sensation – these are not experiences set against some pre-existing ideal, but primary apprehensions of a unitary physicality. (Watermeyer, 2013, p. 61)

Consequently, it is in the intersubjective realm that experiences of embodiment become imbued with social values, and this is as true for children and adults with disabilities as for anyone else. In its narrow form, the social model construed impairment (that is, bodily difference in structure or function), as something untouched, indeed untouchable, by culture, ironically echoing the biomedical view it sought to oppose. But to most psychoanalytic thinkers, if we can succeed in setting aside our own projections about disability, it is clear that embodied experience is shaped by social mirroring, in particular from figures in our formative relationships. Raphael-Leff (1994) emphasises that psychic representations of embodied life do not simply ‘spring from within’, but that we ‘learn our bodies through the hands, faces and minds of significant carers and their bodily ministrations’ (p. 16).

A recognition that embodiment is profoundly mediated by the social and cultural has, in the case of gender, long since taken root in psychoanalytic discourse. In the words of Corbett (2008), ‘genders now come to matter within a less constricting corporeal spectrum’ (p. 838). What this means is that the unquestioned privileging, by some at least, of the symbolic – that is, the sexed body – is well and truly behind us. Gendered embodiment is ‘constituted via fantasy, organic excitability, desire, neuron, muscle, relationality, injury, and practice’ (Corbett, 2008, p. 838). So too disability embodiment. Similarly, contemporary psychoanalytic theory on sexuality understand sexual development as having less to do with drives and anatomy, and more to do with the relational and intersubjective experience between the subject and its objects – and primarily how the (m)other responds to the emerging sexual expressions of the child (Target, 2007).

### **Disability and sex**

As noted earlier, in an atmosphere already thick with unconscious material, adding the conflicted terrain of sex heightens the psychic tension. If some people with disabilities are, in fantasy at least, too shameful to be entitled to recognition as fully human, as ‘part of us’, then surely their participation in our most intimate expressions of inclusion – in sex – must feel out of the question. So it is that the sexuality of people with disabilities has pervasively been shrouded in silence, or denied through the belief that such individuals have no desire or ability to engage in sex (Miligan & Neufeldt, 2001; Esmail, Darry, Walter & Knupp, 2010). Indeed, in their ground-breaking work on disability and sexuality, Kulick & Rydstrom (2015) write of how, in Swedish residential care settings for persons with physical disabilities, a common expression is ‘do not wake the sleeping bear’. Since feelings and fears about our

sexual desirability are often held with such tautness, the threat of shame and rejection never far away, it makes sense that those into whom we project our worst indignity become unthinkable as sexual actors.

According to one view, tragic loss as a central trope of projections surrounding disability contributes to a culturally maintained silencing of the subjective lives of people with disabilities (Watermeyer, 2009; Watermeyer & Swartz, 2008). Subjective struggle relating to both socio-political and embodied experience is less admissible from those whose lives we imagine as painful and damaged. This is paradoxical, but not surprising, as it stands to reason that those into whom we project our darkest anxieties should, in fantasy, have lives too abject to bear thinking about. A range of authors have explored the ways in which patterns of relationship and cultural mores surrounding disability prohibit the discussion of non-normative embodiment, as well as social disadvantage (Olkin, 1999; Thomas, 1999; French, 1993; Wendell, 1997; Garland-Thomson, 2009; Watermeyer & Swartz, 2008, 2016). But as we all know, conversations about our sexual desires and feelings about our own desirability, are never easy. The spectre of rejection, of being unwanted, is seldom far away, waiting to enliven malignant objects that will pour shame on our 'imperfections'. In everyone's socialisation, ideas about sexuality involve representations of what is considered 'normal' and 'abnormal', 'acceptable' and 'unacceptable', and sexual feelings and actions are thus bound up with issues of power and control (Weeks, 2010). The combination of disability and sex, we argue, confronts our unconscious lives with a sort of double jeopardy of reverberating evocations. As noted above, the psychic compromise which often emerges culturally is one of constructing people with disabilities as not being interested in, or capable of, sex. In some cases though, notably that of persons with intellectual disability, the projection is one of hypersexuality and perversion – a fantasy of mindless, degenerate id enactments. Sinason (1992) understands this as, in part, the manifestation of unconscious fears of a world taken over by the swarming reproduction of this, in her view, most feared and hated minority.

Returning to the issue of the silencing of struggle in disability, recent work has related this to psychoanalytic ideas concerning the same phenomenon in racism (Cheng, 2000; Watermeyer, 2016). With her notion of *melancholic suspension*, Ann Cheng (2000) points to how racism in the US positions, among others, African and Asian Americans in an invidious space, both socially and intra-psychically. Carrying a negatively valued public identity, that of blackness, members of these groups are compelled by normalising forces to strive for a cultural ideal,

that of whiteness. But at the same time, the attainment of that ideal is structurally foreclosed (ibid.). What this can create is a melancholic stasis, prohibiting the conscious feeling and expression of grief to do with socially engendered trauma, as well as the political impetus which this can bring. Watermeyer (2016) explores the relevance of these ideas to the psychosocial predicaments of people with disabilities, finding important parallels. Although dominant culture dictates that the bodily ideal can never be achieved by those designated 'disabled', it must nevertheless be striven for, in a manner which draws attention and energy away from the inner world, in so doing limiting the possibility for deepening, self-compassionate embodiment.

In this paper, we use two case studies from a photovoice study to investigate how tropes of disability and sexuality may play a role in the lives of South Africans living with physical disabilities. Taking a psychosocial stance, our interest was both in the intra-psychic impressions left by the distorted sexual socialisation which our participants remain subject to, and the effects of this on their own sexual relationships, participation and fulfilment.

### **About the case material**

Recent work stemming from the project on which the present paper is based, has explored the negative societal attitudes and beliefs of so-called non-disabled people about the sexuality of people with physical disabilities in South Africa (Hunt et al., 2018), and the personal experiences of interpersonal and sexual exclusion of a sample of men and women with physical disabilities (Rohleder et al., 2018). In this article, we draw on the narrative interviews of two participants, Mary, and Bubele<sup>1</sup>, and present a psychosocial analysis of their narratives. We selected these two participants as case studies for our analysis here, because they had experienced their disability from birth or infancy. The majority of the other participants had acquired a disability, most in late adolescence or young adulthood. Thus, these two cases provide us with rich case material to consider the psychosocial aspects of the embodied experience of growing up disabled, and developing a sense of self. Both had a very visible physical disability; Mary was born with a congenital disability, Bubele acquired a disability as a young child, as a result of an accident. Bubele was in his early 20s, Mary was middle-aged. Both were single at the time of the interview. Both identified as heterosexual.

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<sup>1</sup> Pseudonyms have been used

They were from different ethnic and language backgrounds, but both interviews were conducted in English, in which they were fluent.

Photovoice narrative interviews were conducted with both Mary and Bubele. Photovoice is a participatory research approach, where participants are invited to take photographs that represent or illustrate their experience in relation to a specific topic (Wang & Burris, 1997; Vaughan, 2014). The premise on which the research team's decision to use photovoice was made, was that people with disabilities have hitherto been represented – in the main – in negative light in the visual realm. Photovoice, then, would offer an opportunity for these participants to shoot back (Hubbard, 1996) at dominant visual representational regimes, challenging the ideologies which underlie them (Hunt et al., 2019). We provided each participant with a digital camera, and invited them to take photographs of things that represented or were symbolic of their experiences in relation to sexuality. They were also invited to share other visual or artistic outputs, such as drawings or text. Each was then invited to take part in an individual interview, where their chosen representations were used as prompts for narrative discussion. The focus of the interviews was on sexuality, relationships and sexual health, but they followed an unstructured format in that the focus of discussion revolved around the photographs, drawings or writings produced by each participant. Mary and Bubele each gave their consent to take part and for their representations to be used for research purposes and dissemination<sup>2</sup>.

Research interviews typically generate narratives and memories that are consciously remembered and reported on, and do not provide the sort of attention to unconscious processes that a psychoanalytic therapy would involve. Psychosocial research methods such as that of Hollway and Jefferson (2013) or those outlined by Clarke and Hoggett (2009) provide a method to allow for the exploration of affect and unconscious dynamics in research, through observation and the use of free association in narrative interviews, where some unconscious aspects may be revealed. Narrative approaches emphasise the importance of unstructured interviews that follow the narrative flow and associations of the interviewee. Manley (2009) draws on the understanding of Deleuze to argue that a psychosocial emphasis on affect in relation to the data, can only be explored by looking at the interview data as a

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<sup>2</sup> All participants gave consent for their images to be used for academic and public dissemination purposes, and some of the images are publicly available from a project website: [www.disabilityandsexualityproject.com](http://www.disabilityandsexualityproject.com). The content of the website was created with participants' consent.

form of process, beyond its content; how the interviewee think-feels and moves through the space and time of the interview. Manley (2009) further argues for the importance of considering the use of images in psychosocial research as story-telling in the form of words is made possible through “memory images”. Images are then affective material to be reflected on. The use of photovoice could be regarded as a form of free association, where photographs produced on the basis of associations made by participants to their experience of sexuality. Mary and Bubele were invited to take photographs and/or share artistic outputs that represent or are symbolic of their experiences and their feelings and thoughts about their sexual identity. Thus, it invited them as photographers/artists to look both inside themselves (by thinking about their experience, meaning and feelings) as well as looking to the outside world for inspiration for what would capture that meaning or experience. It thus involves an interaction between the internal self and the outside world. As shall be seen in the images presented below, both Mary and Bubele did not portray their experience through bodily image representations, but rather drawing on metaphor to represent their experiences of sexuality. The interviews were unstructured, following Mary and Bubele’s narrative associations to their images.

### **Mary: sexuality as a ‘no entry’ experience**

One image reflected on by Mary was a drawing of a no-entry traffic sign (Figure 1). She began the interview by first reporting that she had initially taken a photograph of such a sign, but that this did not feel right, leading to her producing the drawing instead. She explained that, unlike the photograph, the drawing was something from within, an expression of her subjectivity and embodiment. Here, at the outset, the question of how the social world of meanings relates to interiority is raised. It became clear later in the interview that the sign stood for not being allowed into the domain of sexuality, being told that it would be wrong for her to allow others in, as well as, in fact, unconsciously prohibiting others from her own sexual self.

INSERT FIGURE 1 HERE

Mary explained that she grew up in a conservative Christian home, where sex and sexuality were only considered in the context of marriage and procreation. Because Mary lives with a hereditary congenital disability, at an early age she and her parents were told by health professionals that she ‘could not have children’, because of the risk of heredity. However, in

a seemingly wordless, shared defence, the idea of not having children became transmuted into not getting married, and hence, in the family's world view, not having a sex life. Mary explains:

*although I knew the genetic issues with having children and so on, I never understood why does it have to be that "don't marry"? Why can't it just be, "okay, think hard about having children because the chances of a hereditary carrying over are so high.*

She continued –

*I've got two brothers and no sisters...and they would address...you know, it would be, your children one day, and then when they spoke to me it would be about my career one day.*

Mary's description of this exclusion began with her family, but then moved to her contemporaries, as she explained how, from a young age, she was aware of her girlfriends receiving looks from men which she did not. Instead, the looks she received at first registered sudden recognition of her difference, which was often followed, through interaction, with admiration for her 'amazing' achievements. As she put it, *'the sensuous part goes to someone else'*. Her account was deeply moving at this point, bringing home how, for her, sexual intimacy had always been reserved for others, and not for her.

Conservative Christian morality on sex, one might argue, involves first and foremost a prohibition on desire, not only action. In this context, desire may be experienced by anyone, in part at least, as shameful. But in Mary's case the possibility of desire was already affixed to a body which was not just 'carnal', but also marked as 'malformed'. Beginning with Freud, much has been said about feminine fantasies of mutilation which, attached to sexual desire – as the argument goes – bloom into female self-denigration, beliefs that one is inherently bad and deserving of punishment (Mitchell, 1974). With this work, Juliet Mitchell took a firm stance against psychoanalysis' privileging of the symbolic, asking whether 'self-hating' women were, in fact, not bemoaning their lack of a penis, but rather making sense of the distortions of patriarchy through pointing to differences in embodiment (Corbett [2008] and a host of others continue this divergence from the 'tyranny' of the symbolic). If the madness of patriarchy can be projected by women into their own bodies, it can be re-projected back into the social organisation where it originated, and belongs, thereby loosening the 'body as

destiny' grip of the symbolic. For Mary, though, the symbolic has at least two layers - one of gender, and another of disability. The second comprises her lifelong experience of having a body which is strikingly different to that of others. It may be argued that orthodox religion prohibits (in particular) women from sexual desire and activity in a manner which is bound up with fantasies of female embodiment, with their concomitant projections and defences. Women ought not to have sex because of who (or what) they are – in order to prevent the manifesting of something inherently 'damaged' and 'dangerous'. As we know, the patriarchal project of controlling female sexuality through such forbidding representations has been, to say the least, successful. Being deprived of something because it is scarce, or for some other similar reason, is very different to being denied expressly for the reason of carrying certain characteristics. This is the experience of something not being for me because of something fundamental about who (or what) I am. The shared experience of the denigrated embodiment of womanhood is, even collectively, very difficult to debunk. For Mary, this interacted with a profound difference in embodiment which was all her own. If the sexuality of women in general was responded to with suspicion and regulation, how difficult might it be for a woman with a marked physical disability to make a claim in this domain? With this in mind, we might wonder how Mary was, in Raphael-Leff's (1994) terms, 'taught' her body. In the mysterious moments of 'bodily ministrations' in which sensual possibilities are mediated, unconscious fantasies about the desire and desirability of her body – in part manifesting in the overt prohibitions which came later – must have been present.

Mary was 'learning' her body – what did she learn? A little later in the interview, she explained that the 'no entry' sign was also symbolic of her tendency to keep the possibility of sexual intimacy at a distance, in order to protect herself from pain. She explained her own internal no-entry sign:

*“a few times that I started in friendships with boys or with young men, I would sort of put up the blockades earlier so that I wouldn't get to that point.”*

She went on to add:

*“I didn't want to go further down the path that I knew would just be even more painful. So I would fall madly in love from my side, but then I wouldn't allow even friendships to develop.”*

This latter defence, though not quite universal, is very common indeed in the domain of sexual seeking, involving anxieties around the monumental question ‘will I be desired?’ Visible bodily ‘defects’ are likely to provoke both evocation and projection of these concerns, rendering an intersubjective milieu around physical disability in which unconscious shame makes nuanced thinking unlikely. One possible unconscious narrative within the observer may run as follows: ‘if, as I fear, I am not, or will not, be desired, then who could possibly desire me?’ As is so often the case surrounding disability, this is a (non) engagement which occurs entirely in the realm of paranoid-schizoid fantasy. It is not desirability at play here, but fears of undesirability, which seem to echo around the disabled body – *don’t wake the sleeping bear*. The psychic solution is a dehumanising one, placing prohibitions on feeling, as much as doing.

So securely embedded was the assumption of Mary’s status as a sexual nonentity, that precautions to protect the ‘virtue’ of other teenage girls at her church were foregone in her case. As a youth leader, she was allowed to go on camp co-leading with a young male pastor, while other female leaders would have been required to be chaperoned. In her words, the obliterating assumption surrounding her was that ‘*nothing can happen and nothing will happen*’.

As noted above, the psychosocial story of disability inequality has projective identification at its centre (Watermeyer, 2013). As in other instances of oppressive, collective socialization which combine exclusion with psychic denigration, the question arises as to how an individual may manage to feel differently to that which is expected of him or her. Put simply, if most people one encounters show evidence, subtle or overt, of a powerful assumption that one’s life could only be abject, from where does one muster the means to cultivate a different way to be? The crux of the melancholic predicament lies in the imperative to strive for an unattainable ideal, drawing one towards an illusory goal and, more importantly, away from one’s own embodied reality. If the wounds of the body, emanating from the mirroring and ‘ministrations’ of formative figures, are to be lived, grieved and somehow integrated, an essential starting point is that the body be inhabited. Separating from one’s socialization involves grief, and grieving entails an embodied awakening to that which was stolen, or never possessed. Mary seems to grapple repeatedly with a quandary to do with whether sexuality was taken away from her, or could never have been hers; she reaches for the former, is

taunted by the latter. It is a conundrum, since it is the containing experience of a body that was learned with care that makes full inhabiting of that body, with its pains, imperfections and shames, possible. At this place, formative experiences of being 'looked after' shade into experiences of feeling 'looked at' (Erskine, 1994), with the former deepening embodiment, and the latter disallowing it. Demeaning unconscious experiences of embodiment such as these are, in the lives of many people with disabilities, reinforced by all-too-tangible expressions of denigration by the social world. Mary related her experience with a health professional:

*"So I went to the professor of genetics, and he was very cold. He said, well, if we had already found out the genes that cause [your disability], your abortion would be legalised"*

It is hard to see how this utterance could not be experienced by Mary, if not as murderous, then at the very least as a hatred of her body, obliterating possibilities of the sensual, and of the potential role of the body in causing others to be born. Describing experiences of prejudice in the responses of others, Mary first used the word 'stigma', but then felt it was not the right word. The right word was 'ridicule'.

Of course, experiences of misattunement in sexual socialisation are not peculiar to people with disabilities, as parents are often embarrassed or self-conscious, and may thus turn away from the child's emerging sexuality (Target, 2007). Writing about homosexuality, Lynch (2015) argues that the proto-gay boy receives a degree of misattunement from an early age, where their sexuality is "unsanctioned by others" (p. 140), and they may experience their sexuality as a form of "outlaw" (p. 151). From the evidence of this interview, these remarks apply volubly to Mary's early life experience.

### **Bubele – Sexuality through the 'special' entrance**

Bubele's account was more rational, and contained less description of embodied experience, than that of Mary. However, his interview narrative was littered with reflective questions, seeming to suggest his uncertainty and feelings of ambivalence. His first image (figure 2) was of a wheelchair ramp (Bubele lives with paraplegia), regarding which he described ambivalent feelings. While being something that 'takes away limitations', it also took him back to his school life, of which one part was the catastrophe of separation.

## INSERT FIGURE 2 HERE

Around the world, education policies for children with disabilities have swung dramatically towards favouring inclusive (formerly ‘mainstream’) settings, but segregated ‘special’ schooling remains commonplace. Like so many who live with disability from birth or early life, Bubele was sent as a five year old to a residential special school. Disability studies literature contains a host of accounts in which adults with disabilities bear testimony to having felt evicted from their homes and families as children, as did Bubele. In the previous year he had suffered the accident which left part of his body paralysed, rendering, one might assume, an immense need for nurturing, reparative experiences of handling and care to promote, or re-start, healthy, sensual inhabiting of his body. Instead, he was sent away.

*“due to leaving home so early...because I was five years old and had to live in a boarding school...I almost felt as if I actually lost my place within my own family”*

The other side of the ambivalence Bubele described was to do with the freedom of movement and sense of acceptance he had at the school, as a result of the accessible built environment, and the fact that all children had disabilities. Intriguingly, Bubele then appears to make an unconscious connection between the idea of ramps, of ‘special access’, and the question of his young, developing sexuality.

*“since we got ramps and all of that ... as an individual, upon reflecting on that, it also became almost symbolic of what access was going to mean for me growing up, in the sense that this is where I learnt to relate to girls”*

Being at boarding school meant seeing his father very seldom, and having to wait long periods for an opportunity to ask him questions about his body and sex. He was strongly aware of his identification with, and need for validation from, his father. The functional limitations of many forms of disability are likely, in boys, to become associated with castration. Imagine, then, that this ‘damage’ is punished (symbolically, at least) by a five-year-old boy being sent away from the family and the home, while his siblings are allowed to remain. The ramp in Bubele’s first image seems to suggest a route back in, albeit a ‘special’ entrance, a side door, back to inclusion, and the possibility of successful masculinity. At boarding school, it is likely that Bubele encountered further messaging, both overt and

unconscious, to limit experience of his burgeoning sexuality, emanating from paranoid-schizoid responses to the disability-sex combination (Watermeyer, 2013; McRuer & Mollow, 2012). As studies of sex education in ‘special’ schools have indicated, there is often an avoidant culture or a controlling culture, both conservative and fervently heteronormative (White, 2003; Rohleder, 2010). With rejection from home, and constriction at school, the opportunities for Bubele to grow into his sexual embodiment were limited. He alluded to feelings of fragmentation, and the need to ‘put himself back together’ as a sexual actor.

*“But later on in life I think it represented pieces of myself, ...Because obviously as a male you go through the normal phases of meeting women and not knowing how you’re going to relate to them, and getting to a point where you have your wet dreams and stuff like that. But it’s still not straightforward that, okay, now I can honestly say I identify as a normal human being, if you will, because I’m still confined within my disability”*

Bubele’s second image (figure 3) was that of a church, resonating with his former, idealised idea of home and family, under the care of a powerful, reliable father. The almost mythic description of this home reflected something of his profound anxiety regarding being able to adequately fill the role of *pater familias*.

*“I just thought it represents a lot in terms of tradition, institution and values. ...it almost inspires a family sort of orientated way of engaging with spirituality. So when I thought about it ... as a boy growing up and that at some point I’m going to have a wife and children, and to be able to fit into that sort of setup.”*

#### INSERT FIGURE 3 HERE

This idealised image of secure home life, where one’s sexual individuation was supported, was juxtaposed with his own institutional experience.

*“...a totally and almost alienated place from, you know, a comfortable environment for a child to grow up. ... let’s say if I have any questions about general things that relate to being a boy and growing up, I would have to wait for holidays to ask my father what’s going on, and are you normal and stuff like that. So I was just left by myself to sort myself out”*

Bubele's idealised sense of his father's power was deeply shaken in his middle childhood, when marital conflict set in, resulting in divorce.

*“So I'm thinking to myself, here's this almost larger than life character of my father. I always look up to him and I value him for who he is. But now everything that I'm thinking that I'm going to be aspiring to, it's all falling apart right in front of my very eyes. So I'm thinking to myself, okay, if my father, who is this role model, if you will, has failed at that and being able to make it work and make it last and all those good things, like what chance do I have as a male with a disability?”*

After at first feeling rejected, through not being able to 'measure up' to his father, Bubele then found himself in wonder at how even his potent father was not able to achieve the idealised picture of paternity reflected in the image of the church. This sequence of events, it seems, gave further impetus to Bubele's unconscious conviction that he would have to enter sexual, masculine life via a different route, returning us to the image, and metaphor, of the ramp. Yes, he felt, he could 'enter' the world via ramps, but would this form of masculinity be adequate? The idea of entering, of penetrating, the world has distinct Oedipal echoes, pointing towards Bubele's early defeat and exile by his father, and need to find a way back in (Swartz, 2007). But his way of functioning as a man would be different, and he felt at a loss to predict how this would be received. Here, he takes up the subject position of the female other:

*“It's almost as if he's used to different ways of doing things, so being in his world might mean that I might also have to do things a lot differently”*

And so –

*“Do I start talking to women? Do I just abandon the whole concept about getting into relationships? ... in a relationship am I going to be able to live my entire sexual beingness? Or is it going to be how much she allows me to live?”*

In sum, we see how the idea of 'access' – so ubiquitous in disability discourse – pertains not only to the built environment for Bubele, but also to re-entry, into family life, masculinity, and sexuality. In this final quotation, he alludes to how his exile from the home, and from the

opportunity to emulate his father, also embodied an exile from his own authentic inner life, which he also had to strive to re-enter.

*“Ja, just access into my own being; my own emotions as I grew; my own masculinity and the way I think I was going to be able to relate to the outside world because obviously that is where I was going to ultimately live my entire life, even though I spent most of my life within the special school.”*

There is evidence here of some unconscious awareness of how his socialization, involving eviction from his home and family, as well as physical exclusion resulting from the built environment, brought with it an exile from his own body. The ‘special entrance’ he needed to find and use was, thus, a passage into the mother, the world, women, and his own body.

While seeing this course before him, his words bear evidence of the melancholic snare (Watermeyer, 2016) described earlier – returning to a place from which unitary, integrated embodiment can be built would require successfully denouncing the nondisabled, masculine sexual ideal, a very difficult task indeed.

### **Concluding comments**

As Frommer (2007) states, “being on the wrong side of sexuality’s normative/non-normative divide” (p. 32) can be experienced as psychic dissonance and shame. For both Mary and Bubele, their embodied experience of difference set them, inwardly and outwardly, apart from others. Their sexuality and bodily intimacy either felt foreclosed (more so in the case of Mary) or came with a sense of ambivalence and even trepidation. Both Mary and Bubele spoke openly, honestly and with some sense of comfort and confidence. On the surface they were not sad and would probably not think of themselves as carrying sadness. However, the countertransference of the interviewer for both interviews was that of needing to tread gently and respectfully, to not probe too much. The interviewer experienced a sense of underlying sadness and pain, and the images, strikingly, did not represent themselves, but rather seem to stand for empty spaces, metaphors for their denied sexuality. Both Mary and Bubele report not only on the messages that they have heard and received, but also on how these have come to be incorporated into their sense of themselves, as they feel that access to their sexuality is denied or problematized. However, this is not a passive process; Mary and Bubele do not just incorporate these views as forming part of who they are, but rather question and grapple with these notions, because they do not correctly mirror their actual experience of themselves.

They experience a further layer of oppression as they feel their sexual life to be something of an 'outlaw' to others, and they have to negotiate this external and internal barrier. The result is a sense of loss for what could be or what could have been.

Part of the project of disability activism, in the area of sexuality and in other areas, is the rejection of the pathologizing gaze of the medical model, as we have indicated in the introduction to this article. Given this emancipatory imperative, we acknowledge some discomfort with our retelling of the stories of Mary and Bubele, as they can all too easily (but incorrectly) be read as tales of psychic damage paralleling damage to the body. This would be a misreading. The psychosocial turn in disability studies critiques not only the pathologizing gaze of the medical model but also the possibility that social model/activist approaches to disability may be predicated on a disavowal of the real psychic pain that social exclusion, and how we deal with it, can cause. The psychic pain of oppressed groups is a product not of their own weakness but of a system of oppression, exclusion and disavowal (Fanon, 1986; Watermeyer & Swartz, 2016)

In recent years, crip theory (McRuer, 2006) has emerged as a critical theoretical framework for challenging the demarcation between 'normality' and 'abnormality' and the 'desirable' and 'undesirable' body. Crip theory, similar to queer theory, has emerged as an emancipatory "narrative of attack" (Sykes, 2009, p. 250) about constructions of normalcy. However, as McRuer (2013) argues, crip theory cannot eradicate the prevailing constructions of dis/ability and ab/normality and un/desirability, but can demand a reappraisal of them, making possible more complex, fluid positions. In this paper, we draw on binaries that crip theory seeks to disrupt, because these are the very binary social constructions that Mary and Bubele grew up with and internalized as parts of themselves. Crip theory permits us to think that alternative constructions can be made possible. It highlights the importance for parenting of children with disabilities to provide positive mirroring and build a sense of resilience against the prevailing social constructions of disability and sexuality.

In order to become a sexual citizen (Weeks, 1998), the personal has to be made public and political, so that social belonging can be claimed. The issue is not just for people with disabilities to 'overcome' their sexual oppression, however. There is also contextual work to be done by all who value inclusion. A facilitative environment needs to be created where sexuality in a variety of shapes and forms is recognised, acknowledged and accepted. As

Shakespeare (2000) argues what is demanded is a right to control, access and choice in relation to identity, the body, sexuality and relationships. This is an issue not just for disabled people but for all people.

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