



# Understanding and Exploring the Effects of Informal Care on the Sexual Self: A Disability Perspective

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**ABSTRACT:** This journal edition explores the complex relationship between disability and sexuality for people receiving informal care provided from a family member or partner. Rarely does academic literature explore the personal experience, identity and the private relationships of disabled people, particularly within the context of care. As such both scholars and social workers have largely undermined disabled people's ability to control their own lives; including their sexual identity and intimate relationships within care settings. Within this paper I argue that the extent to which sexual agency can be exercised is influenced by intersecting parts of people's lives, such as having independence and supportive social networks. This paper will explore the complexities of personal relationships amongst disabled people receiving informal care, examining the limitations to intimacy and wider social life. Informal care can be extremely disempowering for both carers and those being cared for, often regulating their lives through the imposition of routine and structure, leaving little room for spontaneity. Therefore, for some disabled people and their carers this regulation and control of everyday life can have a significant impact on personal relationships, self-esteem and independence. Using case studies based on face-to-face interviews, this paper will explore the impact of informal care on personal relationships of people with a range of physical, mental and learning impairments. I propose that academia and social care professionals can learn from the personal experiences of the active disabled voice within research, particularly in relation to exploring intersectionality.

**KEYWORDS:** Disability; Sexuality; Sexual Agency; Informal Care; Intimacy



For many disabled people with complex needs, social care is essential for carrying out everyday tasks such as getting dressed, cooking and washing. Whilst some disabled people receive formal state care, many are still reliant on friends, relatives and often partners to provide essential care for them (Purandare 2003). This type of care is widely referred to as 'informal care' and is predominantly unpaid (Dearden 2001). Welfare provision has often depended on a relationship between both the state and support from social networks such as family members or partners who play a vital role in the both the care system and their loved ones lives.

Much research has shown concern for the impact of caring for both carer and recipient on their wider social lives (Arber and Ginn 1991). Recent studies have shown both formal and informal social care for disabled users have focused on the restrictions of social life, including the effects of isolation and helplessness for carers and recipients (Tarapdar 2007). Social care users often find their everyday routines regulated by rigid care routines and relationships mediated by the provision of care (Beckett 2007). Furthermore there has been increasing research into these issues and recognition within social research itself that care is a complex intersection between public and private spheres (Daly and Lewis 2000). This raises vital questions towards the effects of care on personal relationships.

These studies pose significant academic importance to this under-researched area and begin to draw links between social care and sexuality for disabled people (Beckett 2007). Furthermore, to date, literature has rarely acknowledged disabled people as able to control their own sexual agency and is often heavily focused on abuse and a lack of sexual agency. Tom Shakespeare (1994) suggests that within social research academics have often ignored the personal experiences of disabled people and have spoken on behalf of them. Abberley also recognised that disabled people within social research are often viewed as passive research subjects that fail to question power relations between the researcher and the researched (1987). This has also been a recurrent theme within feminist and more recently Critical Race Theory (CRT) which has critiqued previous forms of literature for not recognising power relations which reinforce colour-blind or sexist points of view. Hylton argues that CRT has enhanced his critical eye and enabled him as a researcher to draw on the theoretical framework to draw on other literature that has critiqued mainstream race research (2012).

This project seeks to draw upon these theories and recognise the importance of the active disabled voice in research. Stone and Priestly suggest that academics working within the dominant paradigms of disability have continued to marginalise disabled people by portraying themselves as the holders of knowledge (1996). Moreover, disabled people's autobiographical accounts are laden with examples of care being given without choice and a lack of consideration to protect the agency of the care user (Beckett 2007). In order to question previous methods of the social analysis of disablement, it is vital as a researcher to engage with an emancipatory form of research that gives participants a platform to voice their experiences. Within this paper I will be discussing the complexities of research into disablement and sexuality by drawing on past literature that rarely challenges the power structures that exist between the researcher and participant. This paper will seek to critique mainstream disability research, questioning these power structures, and instead drawing on perspectives of personal experiences told by the disabled participants.

The structure of this article is as follows. First I will outline some of the academic literature surrounding the topics of disability, sexuality and social care in order to review existing literature within these fields. This is followed by a description of research methods and procedures used during the study, including some of the challenges to conducting research on sensitive topics with potentially vulnerable groups of people. This is followed by a discussion of the several case studies which are divided into a discussion of three themes: independence, social networks and stigmatisation. Finally I will discuss opportunities, limitations and direction for future research in order to contribute to these under-researched fields of study.

## Sexuality, disability and care

The disabled body is often perceived negatively by society, overshadowing almost all other aspects of a disabled person's identity. The concept of the disabled body is central to the idea of power and control as it is the social currency in which people signify power and worth (Gershick 2000). Therefore the treatment of people within society depends on how normative the body is perceived. Foucault's concept of the 'monstrous' (1999) describes sexuality as constituted not by otherness of abnormality, but by the offence it offers to the law in transgressing set guidelines

and regulations. However, sexuality is of course expressed through many different forms and has been recognised in social research as an integral part of human life (Weeks 2003; Merleau-Ponty 1962).

The disabled body is conceptualized in many different ways and generally grouped by physical and psychological impairments (Gerschick 2011). These impairments include mental health, deafness, blindness, Asperger's Syndrome, developmental disabilities and Tourette's, some of which I refer to within this paper. However, the category 'disability' has a long history that has focused predominantly on segregation (Shildick 2002). Beer argues that 'disabled people are 'left on the margins of social life', partly integrated and partly not, anomalous for the remainder of their lives' (Beer 2003:66). It is this separation between disabled and non-disabled people within social life that creates a divide not only within society, but also within social research where disabled people are often excluded as active participants.

Research into the personal experiences of disabled people is a relatively recent phenomenon in academic research and has previously surrounded issues such as abuse and lack of sexual agency. Since the 1990s the term 'disability' has been highly contested and the definition of who lies within the category 'disability' has been highly politicised.

Lunsky and Konstantareas (1998) suggest that there is little research in this area due to misconceptions about sexuality and disability. They argue that this has had a significant impact on how researchers view the value of the sexuality of disabled people, particularly those with developmental disabilities. They also suggest that there may be a negative perception of research in this area, resulting in it being perceived as not worthy of researching. This is due to the perception of a dormant sexual life for disabled people. Researchers may be deterred from researching disabled people for fear the participants won't be able to understand questions, or be capable of participating in the study (Lunsky and Konstantareas 1998).

Research has suggested that the categorisation and labelling process used in social research has been a limiting experience for many disabled people, which have ignored other equally important aspects of an individual's identity. McReur and Mollow (2012) claim that for a person to identify as 'disabled' is a complicated process. The marginalisation of people with a physical or learning impairment shows a focus on disability within a medical context, rarely taking into account

multiple and intersecting identities that make up the self.

The marginalisation of disabled people is inherently linked to societal critique of the disabled body, which is often perceived negatively and overshadowing almost all other aspects of the person's identity.

Foucault (2003) analyses the construction of bodily narratives in relation to power structures, relating to the disabled body, and its punitive deviant perception within the power of normal binary. The body is central in social life; people's treatment within society depends on how normative their bodies are: "One's body serves as a type of social currency that signifies ones worth [...] people with less-normative bodies, such as people with disabilities are vulnerable to being denied social recognition" (Gerschick 2007: 76). This raises questions as to the perceptions of disabled people in society and whether or not they are controlled by what is socially constructed as 'normal'. Disabled people are considered as either in need of protection, or 'abnormal' and often denied sexuality as a result (Milligan and Neufeldt 2001).

Links can be drawn between the representations of disabled bodies, women and black people each sharing experiences of social prejudice from societies that locate the 'problem' with the body (Stone and Priestly 1997). In contrast to this, Oliver argues the social model of disability locates disability within the values, mode of production, political economy and welfare system of society (1990).

Sexuality is a subject that is rarely spoken about in relation to disability. This is a complex issue which is inherently linked to oppressive representations of the disabled body and subsequent regulation of disabled people's agency to exercise a sexual self that is visible to the public eye. Sexuality itself is still a taboo subject, historically being seen as sinful unless it is for procreation (Tepper 2000). Past literature on sexuality has questioned the definition of sexual identity and the relationship between the sexual and the social (Weeks 1985). It was not until the 20<sup>th</sup> century that scholars began to (re-)view sexuality as a natural part of human experience (Foucault 1978).

Foucault argues that sexuality is controlled and regulated by organised power structures limiting how sexuality is exercised. It is expressed through many different ways and is recognised as an integral part of human life (Weeks 2003; Merleau-Ponty 1962). Centuries of oppression have resulted in deeply entrenched norms surrounding sexuality. Foucault's work is inherently linked to the oppression and

otherness of disabled people with particular reference to the disabled body which is segregated from the idea of dominant cultural 'normality'.

Research by Lamb and Layzell (1994) also recognise the unspoken taboo surrounding disabled people and their intimate relationships. They argue that disabled people's emotional and sexual needs are rarely discussed in everyday life and views on sexuality and disability have only be challenged as a result of input from disabled people themselves (Oliver 1996; Barnes and Mercer 1996). This is an argument also supported by Bonnie who suggests "society at best finds the thought of a disabled person being sexually repulsive and at worst presumes we are all asexual" (Bonnie 2004: 125).

Over recent years a number of key activists and academics have begun to conduct researched into the field of disability and sexuality, challenging the idea that disabled people do not exercise a sexual self (Tepper 2000; Shakespeare 2000; 2002). However, it is important to remember that options for exercising agency are still only empowering a small percentage of disabled people, who are able to explore their sexual desires (Smith 2004). Smith suggests that there are a number of reasons underlying why such a small number of disabled people feel they can exercise a sexual self, relating to social and cultural barriers such as the perception of a lack of agency, stigmatisation of disability and a negative public reaction to disability. It has been recognised by activists and scholars alike that to exercise sexual freedom and happiness is a fundamental human right (Geschick 2011). More recent publications have continued to explore the complexity of disability and sexuality through an interdisciplinary approach (McCarthy 2011; Oliver & Barnes 2012).

However, few scholars have explored these issues within the context of care. The act of care in itself represents uneven power structures in which disabled people are seen as passive, powerless and dependent on others (Silvers 1995). This argument is also shared by Paul Abberley (2002) who highlights the disempowering effect day-to-day exposure to medical interactions can have, which can be problematic for bodily agency and integrity for disabled people. However, the perspective of disabled people receiving care has largely been left out of care research. Lloyd in particular highlights the importance of feminist research on caring that recognises the experience of disabled women in care as doubly disadvantaged as their bodies are scrutinised against traditional notions of femininity and sexuality (2001).

Disabled people within an environment of social care often have very little agency, both in terms of exercising sexuality and having control over the process of care itself. Beckett (2007) argues that for care to become empowering, it must be linked to a framework of rights. This supports a body of literature claiming that care is related to a lack of agency, control, and ability to control basic social functions (Beckett 2007; Hughes 2007; Fine and Glendinning 2005). Both in the context of a care home or for social care users receiving support within their own homes, research has shown that individuals have very little control over their own destiny.

There has been increasing recognition in recent years of non-traditional types of care for disabled people, often carried out by family members or partners (Beckett 2007). This creates a blurred boundary between the relationship between personal lives and care for disabled people. Beckett (2007) argues this lack of clarity on the definition of care is problematic for both carers and care receivers, where both are constrained and have limited choices. This level of constraint may impact on personal relationships between carers and care givers; however, the effect this has on sexuality is largely underexplored.

Intersecting elements of disabled people's lives can affect both dating experiences and levels of sexual behaviour (Kef and Bos 2006). There is a lack of research within social science on the sexual lives of disabled people and the experiences of intimacy and sexual and romantic relationships have been ignored. Having a disability may result in moderate to severe restrictions in the performance of social roles related to work, family, leisure and relationships. Kef and Bos also suggest that dating occurs much less often amongst people with a physical disability (2006).

Research exploring sexuality and disability has acknowledged the profound effect that disability has on sexuality. However, the impact that care has on disabled people's lives is still underexplored and in need of further research to explore how disability and sexuality intersect with elements of care such as personal relationships, marriage and family life. This paper will explore some of these issues in order to draw links between sexuality, disability and social care.

## Methods

This paper is based on empirical research using semi-structured interviews. People with a variety of different impairments were interviewed on their experiences

of informal social care and exercising sexuality. In this research project, ten semi-structured interviews were conducted; eight in person and two by phone on the request of the participants. These interviews were conducted between September 2012 and February 2013 in Brighton and Hove, forming the data for my dissertation thesis at the University of Sussex. Recruitment of participants was a particularly challenging process as the majority of respondents were considered a 'hard to reach' group not often not able to access public spaces due to their impairments where advertisements about the research may be displayed. Most respondents were recruited through a gatekeeper who enabled me to gain the trust of participants and reassure them of the legitimacy of the research with relative ease. This approach to recruitment was particularly beneficial for the project due to the sensitive topic and involvement of potential vulnerable respondents. The rest of respondents were recruited online through forums once permission had been granted from the owners of the sites. This enabled respondents who were not so mobile to still be able to partake in the research.

Semi-structured interviews allowed interviewees the freedom to discuss their experiences in detail and at their own time (Bryman 2001). The interviews were made as informal as possible in order to make participants feel comfortable. It was vital to use a more intimate approach to interviews in order to limit embarrassment and make the respondents feel comfortable (Stewart, et al. 2007).

The research focused on personal experiences of disabled people through a qualitative method of data collection. To avoid filtering experiences and gain an accurate wider view, qualitative research into people with disabilities' experiences appeared the most effective way to produce valid data (McCarthy 2000). Thematic analysis was then used in the analysis of the data, resulting in three main: stigmatisation, social networks and relationships.

The decision to use empirical research methods is attributable to both the sensitive topic and the detail that I felt this topic needed to provide any significant understanding of the personal lives of disabled people. Research conducted in the 1990's had previously failed to ground their work within an epistemological framework, often being considered as oppressive to the disabled participants involved (Abberley 1987). Therefore this research sought to firmly locate itself within an emancipatory paradigm that puts profound importance on giving a voice to the personal as political, and endeavouring to focus on personal experiences of participants.



The use of semi-structured interviews gave respondents an opportunity to voice their individual experiences of participants at their own pace, and supported emancipatory research techniques. A longer, less structured interview enabled a practical benefit to the self-empowerment of participants and removal of barriers that may prevent them from taking part in the research. This technique is much more suited to small scale projects to reduce any disabling barriers (Barnes 1991; Fontana and Frey 2005).

## Independence

Independence was a key aspect in all the respondents' lives, relating to individual agency and self-esteem. This theme was identified by respondents in reference to the extent to which they could carry out everyday activities without the care of another person, usually a family member or partner. Several respondents felt that receiving both formal and informal types of care affected their ability to structure their day and carry out spontaneous activities or outings with friends and family. Respondents described how care amongst partners or close family members had changed their relationship. Many often struggled to distinguish time spent together intimately or as friends and time within the roles of carer and recipient.

The close relationships respondents had with informal carers often impacted on self-esteem and the ability to separate their disability from the rest of their identity. Several respondents felt their lives had become dominated by structure, routine and often control, as much of their day was spent carrying out essential tasks, with few opportunities for leisure or relaxation. I will illustrate some of these issues using case studies of respondents within the study who experienced physical, mental and learning impairments. In the accounts below issues of the structure, control and unpredictability of the need for care illustrate how personal relationships can be affected by the reliance on informal care.

## Impact on the family unit

Alexia has Chronic Fatigue Syndrome and is married with two teenage children. Alexia's impairment can fluctuate from day to day, meaning some days she can carry out everyday tasks with very few symptoms and on other days she may be

unable to leave her bed due to fatigue. Alexia also expressed signs of depression relating to the limiting effects of her impairment, resulting in feelings of worthlessness and lack of self-esteem. This was often due to the unpredictable nature of her impairment which left her unable to make plans or be sure she would be able to carry out tasks on certain days. She was heavily reliant on close family and her husband to look after the children on days when she was unable to, which left her with a feeling of helplessness. This was also a contributing factor to excessive strain on both her marriage and family life.

'I'm reliant on my husband and daughter, they have to do everything when I'm confined to my bed, I just feel helpless, completely useless.' Alexia described how the reliance on her husband for care had impacted their sexual relationship as she was often unable to be intimate. 'When I'm really ill I can't even make love to my husband, it's really impacted on my relationship, all he seems to do is care for me it's very un-erotic and can be quite depressing.' The relationship of Alexia's husband as both a partner and carer had impacted upon the marriage not only financially, but upon intimacy in the marriage. The lack of permanence in the severity of her illness meant that she was not eligible for formal social care. Therefore the impact was that both family life and her marriage were regulated by unpredictability and the loss of spontaneity that she felt would benefit her close relationships.

### Restrictions of care on everyday life

Jane has Multi Degenerative Disk Disease, the symptoms of which include poor mobility, severe back pain and incontinence. She is a wheelchair user and lives alone. Jane has a formal carer who comes in once a day to help with breakfast and getting dressed which she does not like as the carer often arrives late, restricting her ability to plan the rest of her day. Jane has had a number of partners over a period of time that have come and gone; unable to cope with the role of caring for her. Jane felt as though her disability 'owned her' and this was often the cause of her relationship breakdown and topic of conversation with friends. 'I am fiercely independent, probably trying to prove to me and to other people that the disability doesn't own me'. Despite her determination for independence, Jane had spoken in length about her depression over the limitation of her impairment of both her social and sexual life. She also felt that when talking to friends, people

raised little conversation that was not related to her disability, resulting in loss of self-esteem.

‘When I see people I haven’t seen for ages and they ask me how I’m getting on and what surgery I’ve had, it’s like there’s more to me than that’. Jane indicated that often when she socialised with people she did not see often, her disability was the main topic of conversation leaving her feeling ‘othered’ amongst her friends. Jane felt the impact of her impairment had not only resulted in a lack of meaningful, supportive social networks but had hindered her ability to settle down with a partner.

### Age and the complexities of growing up with a parental carer

Zoe is 19 and has Spinal quadriplegia C3–C1<sup>1</sup>. She is a wheelchair user and has a PA (Personal Assistant) with her during the day to help with mobility and day to day tasks. During the evenings and other times when her PA is not with her, she is cared for by her dad who is a single parent. Zoe has a strong relationship with her dad and they often talk openly when talking about Zoe’s sexuality. However, the relationship between Zoe and her father had become increasingly complex after she had reached puberty. She felt the caring relationship she had with her dad had become ‘inappropriate’ and ‘uncomfortable’, particularly when helping her wash and get dressed. Zoe expressed how the relationship of her dad as a carer had made her feel desexualised and childlike.

The complexity of the parental care relationship had furthermore deepened when Zoe had met her current partner. Her emerging sexual agency had resulted in the role of care being taken over by Zoe’s boyfriend. She felt the intimacy of her caring routine such as washing were no longer appropriate for her dad to undertake ‘I’ve had people around me, like my dad and family looking after me. They still make me feel I’m not an attractive person and should be kept in the dark’. Zoe felt the process of care being undertaken by a family member was a desexualising experience that had impacted on her ability to exercise an intimate relationship with her boyfriend. This is a concept that Cole and Cole (1993) argue has desexualising experiences on libido, and self-esteem affecting the disabled person through their sexual lifespan. The clinical process of care carried out by her father had caused

Zoe to feel desexualised. The overall reliance on care had subsequently changed the dynamic of the relationship with her dad and strengthened the intimacy between her and her current partner.

## Stigmatisation

Based on personal experience, stigmatisation of the label 'disability' was an issue that all the participants recognised. Mollow and McReur (2012:1) suggest 'rarely are disabled people regarded as either desiring subjects or objects of desire'. Participants had encountered negative comments about their disabilities from a range of different people in their lives, including strangers in the street, co-workers and even family members. Often friends and family would have very little understanding of the importance of sexual agency, showing disapproval when they entered into a relationship. Howard Becker's (1963) theory of deviance argues that individuals can break the rules that are agreed by a group of people, but as a result are labelled as 'outsiders'. Becker's study can be linked to the participants within these case studies, with many experiencing hostility about exercising a sexual self. Participants were often questioned by both members of the public and their own family friends, placing stigma on both their identity as a person with a disability and as someone who exercises a sexual self. Becker's identification of individuals as rule breakers being labelled 'outsiders' by dominant societal norms is inherently linked to society's regulation of disabled people, particularly when exercising sexuality. One respondent named Julie had particularly harboured painful feelings of low self-esteem and lack of self-worth relating to an internalised oppression resulting from her rejection of the label disability. These negative feelings had resulted in a difficulty coming to terms with being diagnosed with a disability later in life.

### The stigma of the label

Julie has severe dyslexia, but was not diagnosed until she was in her mid-30s. She had also just recently been diagnosed with depression as a direct result of not being able to cope with her diagnosis of dyslexia. She felt by being diagnosed with both a mental health condition and learning impairment, both labels would dis-

advantage her in her life. 'It took me a long time to get used to having a disability, I felt like it would make me appear incapable to myself and to others'. Julie's struggle to come to terms with the diagnosis of both impairments was founded on her preconceptions of the stigmatisation of the label 'disabled'. The category 'disability' has a long history that has focused predominantly on segregation where people feel that they will become an 'outsider' (Shildrick, 2002).

For Julie, the biggest impact upon her life was the stress of coming to terms with diagnosis, and the label 'disability'. This had impacted on her relationship with her partner due to her acute lack of self-esteem and feelings of worthlessness. Julie described her relationship with her partner being about going out and having fun with their friends. Whereas after her diagnosis with dyslexia, and subsequently depression, she described herself as introverted and lacking self-esteem, which had impacted on her confidence within the relationship. Hahn suggests that the effects of stigmatization may cause powerful psychological barriers that may create obstacles for the disabled men or women in love and marriage (Hahn 1981). The psychological obstacle was founded upon her struggle to connect with the label 'disability' largely due to her diagnosis later in life. When asked how she felt her disability related to her sexual identity she replied 'I think it does, I mean although personally more the transition of accepting that I would have a disability, it's a very big thing for me to accept the sort of label side of it; just the effect on my self-esteem'. Julie clearly identified with stigmatisation through the label of disability which impacted on her self-esteem, 'I felt like it was quite a transformation over a period of time which definitely impacted on my self-esteem'. Becker's (1963) suggestion that minority groups are labelled, creating a self-fulfilling prophecy where the individual internalises and becomes the label. Julie's reluctance to adopt the label 'disability' was due to fear of feeling, and being perceived as incapable if she adopted the label of having a disability.

Goffman (1963) argues that a coping strategy regarding social stigma is withdrawal from society. He suggests that society develop places for stigmatised individuals, which he refers to as 'total institutions' (Goffman 1961). It was evident in this research that the category disability in itself is a form of 'total institution', which is controlled and regulated, limiting the experience of sexuality for many disabled people. Regulation can occur in many different ways including limiting access to locations to meet partners or exercise a sexual self.

## Public reaction to disability

Rosie was diagnosed with ME (Myalgic Encephalopathy)<sup>2</sup> when she was 19; she is now a partial wheelchair user. Now age 25, much of the interview had been about comparing her life before and after she was diagnosed. The majority of these comparisons were made in relation to how she is perceived in public by strangers. She explained how people talk to her in the street, often at night when out socialising, asking about intimate details relating to her sex life. 'There's usually questions about 'does it work' [to have sex], you get people saying "can you have sex?" People assume your sex life is going to involve hoists'. Rosie experienced a surprised reaction when she did tell people about her long term partner, 'People come up and are really surprised when I mention I have a boyfriend, and say "oh well done"'. Rosie's experiences indicated a wider public perception of disabled young people as passive, incapable of having a sexual relationship and needing care. She felt that because her disability was not visible unless she was using her wheelchair, she had a duty to inform people about how having a disability should not affect sexual agency.

Rosie also expressed the complexity of online dating as a person with a disability. She had created an online dating profile after being diagnosed with ME as she felt it was an easy and convenient way for her to meet people. Several times she experimented with disclosing that she was disabled, and not listing her disability. 'It's difficult deciding whether you mention your disability or not. When I did, I mainly got disabled people replying. I thought this was weird [...] it doesn't mean we're going to have anything in common'. When Rosie listed her disability, mainly disabled people replied, indicating that there may still be stigma attached to disability when looking for a sexual partner. Morris argues that "We can insist that society disables us by its prejudice and by its failure to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to conclude in our own oppression (1991:183). Rosie's experience with the dilemma of whether to disclose her disability on online dating sites was due to past experiences of prejudice towards her disability when meeting potential partners in the past. She felt that when she did disclose her disability, only other people who were also disabled would reply; suggesting that some disabled people may feel that prejudice has limited opportunities of choice to find a potential partner. There-

fore Rosie's experience may evidence that some disabled people feel they may only be able to enter a relationship with someone who has had a shared experience to them, rather than feeling able to choose a partner based on compatibility. The feminist slogan 'the personal is political' is inherently linked to this argument where the personal experience of disabled people is connected to larger political and structural attitudes.

## Social networks

The ability to interact with a social network of friends is an important aspect in many people's lives, regardless of whether they have a disability or not. However some respondents within this study indicated that having a close and trusted friendship was a vital aspect of their sexual self. Several respondents felt they had a group of friends who would support them in all aspects of their lives, including sexuality; this was a vital part of reassurance for them. Social networks were expressed by all participants as an important aspect of confidence, independence, being able to meet potential partners and discuss love and relationships amongst friends. However, despite the importance of social networks, it must be acknowledged that several of the case stories previously discussed highlighted examples of friends and family showing a lack of recognition of the respondent's life beyond their disability. This resulted in frustration and resentment from participants and highlights the complexity of the role of social networks and the need for a balance between having someone who is understanding and supportive, but also recognising that disability is only aspect of their identity.

## Friendship as positive regulation

Joanne has bipolar disorder<sup>3</sup> and lives with her husband and two young children. Her positive experiences of social networks with friends were vital to providing support for her impairment. Joanne used friends as a support network to identify when her mental health condition was getting, in her words, 'out of her control'. 'People monitor what I'm up to because it sort of relates to where my brain's working and that might be when I'm having a little up time'. Joanne's symptoms are common amongst people with bipolar who often experience ups (known as

mania) and downs where they can feel much less active. During what Joanne defined as a particularly 'high' phase, she experienced risk behaviours such as an uncontrollable libido and recklessness, so she relied on friends to support her to keep her bipolar under control. In the past her high libidos resulted in her having an affair, so she relied on friends to help her rationalise the situation. 'I sort of had a little affair and in which people thought oh she's going a bit loopy because that's not right is it?' Social interaction for Joanne was a direct support for both her disability and sexuality to be regulated and controlled by those around her.

### Socialising as a way to meet partners

Christine has Tourette's syndrome<sup>4</sup>. She receives negative attention when out in public from people who do not understand her disability. Christine's 'ticks' cause her to make involuntary physical and vocal movements that are often unusual and alarming to strangers. Christine expressed how she would like to find a partner, but feels people are often deterred by her impairment. She also stressed the importance of a close group of friends to socialise which is vital for her confidence to find a partner. 'It's hard to meet people, when I'm with my friend I'm a lot calmer so my ticks are less frequent and people are more likely to approach me'. Christine's close social networks and supportive group of friends was an important stage in socialising to meet a partner. She suggested that her disability had stopped her from getting a partner in the past and was the cause of several relationship breakdowns. 'I've never had much luck with women, people are fine with it at first but then they seem to not cope if you're down about it [her disability]'. Christine identified that her disability was preventing her from exercising a sexual self and meeting a potential partner due to lack of understanding about her disability.

### Conclusion

The findings from the case studies reported in this article represent the importance of examining intersectionality in the lives of disabled people. Past literature on disability, sexuality and informal care has tended to ignore the personal experiences of disabled people, particularly surrounding sexual agency. Three main



themes were uncovered in the data, offering explanations to the links between sexuality and disability; these were independence, stigmatisation and social networks. These themes discussed intersecting sections of respondent's lives, often not directly linked to sexuality, but inherently linked to an overall sense of self-esteem and wellbeing. The range in complexity of different impairment will inevitably bring varied experiences. The findings in this article illustrated the unpredictability of impairments such as Chronic Fatigue Syndrome and the effects of living with a fluctuating impairment on personal relationships. Unpredictability in care routine was often a cause of what some participants described as an 'extra burden' on the care process.

The data collected in this study has found that there are several intersections between elements of social life and sexual agency. This was related directly to impact on sexual agency and the extent to which respondents felt confident exercising a sexual self. Stigmatisation, lack of independence and pressure of informal care on partners all contributed to the limitation of the sexual self. The extent to which care routines allowed participants to be independent impacted on self-esteem, which was a central issue to all of the themes discussed in this paper. Self-esteem was often linked to a feeling that their impairment had overshadowed other parts of their identity. The support, or lack of support from social networks was linked to the need for having both an understanding of their impairment, but equally acknowledge aspects of their identity beyond disability. The importance of recognising these intersecting themes illustrates the complexity that disability and care bring to sexual relationships. For many, this relates to stigmatisation and public perceptions, which were felt to limit participants more than the actual impairment itself. 'The social model of disability identifies systematic and attitudinal barriers for disabled people that contribute to the exclusion of disabled people from society. 'Disability' as a label is a source of oppression which places significance on the limitation of the mind or body. The social model of disability recognises that disabling barriers are socially constructed rather than being organised by a person's impairment itself (Scope 2014)

This article demonstrates the importance of examining the personal experiences of disabled people receiving informal social care. The findings indicate not only complexities surrounding personal relationships with carers, but the impact of public perceptions of disability on sexual agency. It is articulated in this article

how the perspective of personal experience in social research can strengthen understanding of informal care and sexuality. The use of the emancipatory paradigm within the research and the commitment to conducting emancipatory research techniques illustrates my politicised action in challenging past roles of disabled people in social research. Touraine also argues that participant observation may only provide 'light touch' data that does not illustrate a commitment to the historical struggle and movement of research participants (1981). As a researcher interested in disablement, it is vital that the research process itself is challenged and the voices of participants are heard in order for oppressive practices to be challenged. My decision to engage in emancipatory research techniques is used to highlight the importance of research that engages with the personal experiences of disabled people, rather than speaking on their behalf. I have proposed during this article that academia and social care professionals can learn from using emancipatory techniques in order to promote the importance of agency for disabled people and those receiving social care.

The overall negative perception of disabled people in the public eye and its potentially damaging effects was a prominent finding. Recent government welfare cuts have directly impacted on disabled people and undoubtedly had an effect on attitudes toward people with disabilities. This article highlights how participants were scrutinised in the public eye, often being asked to justify different elements of their lives including intimate details of personal relationships. Oliver argues that the social model of disability is located firmly within the political economy and welfare system in society (Oliver 1990). This negative public perception of disabled people has been shown in this research to impact on self-esteem and undoubtedly effecting sexual agency, personal relationships and confidence of disabled people.

Although key debates within the fields of sexuality, disability and social care have touched on issues of sexuality amongst disabled people, rarely does this literature illustrate the experiences of disabled people across all age groups. Research has seldom examined the intersectionality of disability, sexuality and social care and has largely been delayed in response to adopting emancipatory research techniques. The development of research within these fields and careful consideration to personal experience will greatly assist with future understanding of the intersection between disability, sexuality and informal care.

## Endnotes

- <sup>1</sup> Spinal quadriplegia C3–C1 is a spinal cord injury resulting in either complete or incomplete quadriplegia, where voluntary movement and sensation of the limbs is severely limited.
- <sup>2</sup> Myalgic Encephalopathy (ME) is a term used to describe people who feel that Chronic Fatigue Syndrome is too general and does not reflect the severity and different types of fatigue. It highlights that fatigue is just one of many symptoms that can vary from day to day.
- <sup>3</sup> Bipolar disorder, formerly known as manic depression, is a condition that affects your moods, which can swing from one extreme to the other.
- <sup>4</sup> Tourette's syndrome is a neurological condition affecting the brain and nervous system that is characterised by a combination of involuntary noises and movements called 'tics'.

## References

- Arber, Sara, and Ginn, Jay. 2004. *Gender and Later Life*. London: Sage.
- Abberley, Paul. 1987. "The Concept of Oppression and the Development of a Social Theory of Disability", *Disability, Handicap and Society* 2: 5–21.
- Abberley, Paul. 2002. "Work, Disability, Disabled People and European Social Theory." In *Disability Studies Today*, edited by Colin Barnes, Mike Oliver and Len Barton, 120–138. Malden: Blackwell Publishers Ltd.
- Barnes, Colin. 1991. *Disabled People in Britain and Discrimination*. London: Hurst and Co.
- Barnes, Colin, and Mercer Geoff. 1996. *Exploring the Divide: Illness and Disability*. Leeds: The Disability Press.
- Becker, Howard. 1963. *Outsiders: Studies in the Sociology of Deviance*. New York: Free press.
- Beer, David. 2003. "The Illness and Disability Experience from an Individual Perspective". In *Willard and Spackman's occupational therapy* edited by Elizabeth Crepeau, Ellen Cohn and Babara Boyt Schell, 57–68. Philadelphia: Lippincott and Williams.
- Beckett. Clare. 2007. "Women, Disability, Care: Good neighbours or Uneasy Bedfellows?" *Critical Social Policy* 27: 360–380.

- Bonnie, Selina. 2004. "Disabled People, Disability and Sexuality" in *Disabling Barriers, Enabling Environments* edited by John, Swain, Sally French, Colin Barnes and Carol Thomas, 125–132. London: Sage Publications.
- Bryman, Alan. 2001. *Social Research Methods*. London: Oxford University Press.
- Daly, Mary, and Lewis, Jane. 2008. "The Concept of Social Care and the Analysis of Contemporary Welfare States", *British Journal of Sociology* 51: 281–98.
- Dearden, Chris, and Becker, Saul. 2001 "Young Carers Needs, Rights and Assessments", in *The Child's World: Assessing Children in Need* Horwath, edited by Jan Howarth, 221–233. London, Jessica Kingsley.
- Fine, Michael, and Glendinning, Caroline. 2005. "Dependence, Independence or Interdependence? Re-visiting the Concepts of "Care" and "Dependency"" *Ageing and Society* 25: 601–21.
- Foucault, Michel. 1978. *The History of Sexuality Volume 1: An Introduction*, United States: Random House.
- Foucault, Michel. 1999. *Abnormal: Lectures at the College de France*. Picador: New York.
- Foucault, Michel. 2003. *Society must be Defended*. New York: Picador.
- Fontana, Andrea, and Frey, James. 2005. "The Interview: from Neutral Stance to Political Involvement". In *The Sage Handbook of Qualitative Research* edited by Norman, K Denzin, and Yvonna, S Lincoln, (3rd ed), 695–727. Thousand Oaks, CA: Sage.
- Gerschick Thomas. 2000. "Towards a Theory of Disability", *Signs* 25: 1263–1269.
- Gerschick, Thomas. 2007. "The Body, Disability, and Sexuality" in *Handbook of New Sexuality Studies* edited by Steven Seidman, Nancy Fischer, and Chet Meeks, 75–83. Routledge: Oxon.
- Goffman, Erving. 1963. *Stigma: Notes on Management of Spoiled Identity*. London: Penguin.
- Goffman, Erving. 1961. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York: Doubleday Anchor.
- Hughes, Bill. 2007. "Being Disabled: Towards a Critical Social Ontology for Disability Studies" *Disability and Society* 22: 673–68.
- Hylton, K. 2012. "Talk the Talk, Walk the Walk: Defining Critical Race Theory in Research", *Race Ethnicity and Education* 15: 23–41.
- Kef, Sabrina, and Bos, Henny. 2006. "Is Love Blind? Sexual behaviour and Physical

- Adjustment of Adolescents with Blindness”. *Sexuality and Disability*, 24: 89–100.
- Lamb, Brian and Lazell, Sarah. 1994. *Disablement in Britain: A World Apart*. London: Scope.
- Lunsky, Yona and Konstantareas Mary. 1998. “The Attitudes of Individuals with Autism and Mental Retardation towards Sexuality”, *Education and Training in Mental Retardation and Developmental Disabilities* 33: 24–33.
- Lloyd, Margaret. 2001. “The Politics of Disability and Feminism: Discord or Synthesis”. *Sociology* 35: 715–728.
- McCarthy, Michelle. 2000. “Sexual Experiences of Women with Mild and Moderate Intellectual Disabilities”. *Journal of Intellectual Disability Research* 44: 384–384.
- McCarthy, Michelle. 2011. “Prescribing Contraception to Women with Intellectual Disabilities: GPs attitudes and practices”. *Sexuality and Disability* 29: 339–349.
- McReur, Robert and Mollow, Anna. 2012. *Sex and Disability*. Duke University Press: Durham.
- Merleau-Ponty, Maurice. 1962. *Phenomenology of Perception*. London: Routledge Classics.
- Milligan, Maureen, and Neufeldt, Aldred. 2001. “The Myth of Asexuality: A Survey of Social and Empirical evidence”. *Sexuality and Disability* 19: 91–109.
- Morris, Jenny. 1991. *Pride against Prejudice*, London: Women’s Press.
- Oliver, Mike. 1989. “Conductive Education: If it wasn’t so sad it would be Funny”. *Disability, Handicap and Society* 4: 197–200
- Oliver, Mike. 1990. *The Politics of Disablement*. Basingstoke: Macmillan.
- Oliver, Mike. 1996. *Understanding Disability: From Theory to Practice*. Basingstoke: Macmillan.
- Oliver, Mike, and Barnes, Colin. 2012. *The New Politics of Disablement*, Tavistock: Palgrave Macmillan.
- Purandare, Nitin, Burns, Alistair, Challis, David. 2003. “Perceived Inadequacy of Current Psychogeriatric Service Provision to Care Homes in the United Kingdom.” *International Psychogeriatrics* 15: 172–172.
- Scope, 2014. *The Social Model of Disability* [Online] Available at: <http://www.scope.org.uk/about-us/our-brand/social-model-of-disability> [Accessed 27 January 2016]
- Shakespeare, Tom. 1984. “Cultural Representation of Disabled People: Dustbins of Disavowal?” In *Disability Studies: Past Present and Future*, edited by Len Barton

- and Mike Oliver, 283–219. Leeds: The Disability Press.
- Shakespeare, Tom. 2000. “Disabled Sexuality: Towards Rights and Recognition” *Journal of Sexuality and Disability* 18: 159–166.
- Shakespeare, Tom. 2002. *Disability/Postmodernity: Embodying Disability Theory*, London: Continuum.
- Shildrick, Margrit. 2002. *Embodying the Monster: Encounters with the Vulnerable Self*. London: Sage Publications.
- Silvers, Anita. 1995. “Reconciling Equality to Difference: Caring for Justice for People with Disabilities”. *Hypatia* 10: 30–55.
- Smith, Bonnie. 2004. Introduction to *Gendering disability*, by Bonnie Smith and Beth Hutchinson (eds). New Jersey: Rutgers.
- Stewart, David, Shamdasani, Prem, and Rook, Dennis. 2007. *Focus Groups: Theory and Practice* (2nd ed), Thousand Oaks: California.
- Stone, Emma, and Priestley, Mark. 1997. “Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers”. *British Journal of Sociology* 47: 699–716.
- Tarapdar, Saima. 2007. “I Don’t Think People Know Enough About Me and They Don’t Care: Understanding the Needs of Young Carers From their Perspective.” London: Open University’s Research Centre.
- Tepper, Mitchell 2000. “Sexuality and Disability: The Missing Discourse of Pleasure” *Sexuality and Disability* 18: 283–290.
- Touraine, Alain. 1981. *The Voice and the Eye: An Analysis of Social Movements*. Cambridge: Cambridge University Press.
- Weeks, Jeffrey. 1985. *Sexuality and its Discontents: Meanings, Myths & Modern Sexualities*. London: Routledge.
- Weeks, Jeffrey. 2003. *Sexuality*. 2nd ed. London: Routledge.
- Wendell, Susan. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge.