

The cover features a white background with several teal lines. One line starts from the top left and curves downwards to the right, passing through two pink circles of different sizes. Another teal line starts from the top right and curves downwards to the left, passing through a larger pink circle. A third teal line starts from the bottom right and curves upwards to the left, passing through a large pink circle that is partially cut off by the right edge of the page. All pink circles have a teal outline and a teal shadow effect, giving them a 3D appearance.

# **(S)exploring Disability**

**Intimacies, Sexualities, and  
Disabilities**

**A Research Summary**

**Kirsty Liddiard MA**

## Acknowledgements

While my name may be alone on the front cover of this Research Summary, I am by no means its sole contributor. Rather, there are a number of people who contributed to the research who deserve to be both acknowledged and thanked here.

Firstly, I show extensive gratitude to all of the people who warmly contributed their stories, histories, and experiences. Without this willingness to share, the research would not have even been possible. In the same vein, I would like to extend great thanks to Research Advisory Group members who offered their time, support and commitment. This piece of research looks very different because of their input, influence and expert knowledge.

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I also show extensive gratitude to the Ethel Louise Armstrong Foundation, which through a Postdoctoral Fellowship at the School of Disability Studies at Ryerson University, Toronto, is funding an important body of work which will ensure that the knowledge produced through this research reaches those at its core – disabled people. This research summary is just the beginning of this work.

**If you have any questions about anything you read in this Research Summary, or would like to know more, please don't hesitate to get in touch:**

**Kirsty Liddiard**  
**Postdoctoral Research Fellow**  
**School of Disability Studies**  
**Ryerson University**

**Email: [kirsty.liddiard@ryerson.ca](mailto:kirsty.liddiard@ryerson.ca)**  
**Phone: 416-979-5000, Ext. 3037**  
**Office: SHE 571, 99 Gerrard Street East, Toronto, ON M5B 2K3**  
**Mail: 350 Victoria Street, Toronto, ON M5B 2K3**



## Introduction

This Research Summary corresponds to a piece of doctoral research which explored disabled peoples'<sup>1</sup> experiences of sex and relationships. The research took place over 3 years (2008–2011) in the south east of England, UK. The purpose of this Research Summary is to provide a concise overview of the research and detail its key findings for a wide range of audiences: disabled people, their allies and organisations; health and social care staff; students and academics; and anyone with an interest in disability and/or sexualities. As well as offering key findings from the research, this Research Summary provides information about the background to the research, its context, and how it was carried out. If you don't feel you need to know this information, please go straight to page seven for the research findings.

## What is the background to the research?

Disabled people have a sexual history marked by oppression, prejudice, discrimination, and violence. In the past much of this sexual history has been largely overlooked within both academic and activist contexts in favour of a focus on disabled peoples' social and political histories; for example, campaigning for civil rights; antidiscrimination legislation; equal access to education; community integration, and environmental accessibility. This necessary focus upon disabling environments has marginalised disabled peoples' sexual politics. Therefore, a lack of knowledge exists around the inequalities that many disabled people experience within their private, sexual, and intimate lives.



Photo: Disability activism 'March for the Alternative', London 2011

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<sup>1</sup> This Research Summary uses the terms 'disabled people' and 'disabled person' rather than 'people first' terminology such as 'people with disabilities' or 'person with a disability'. This reflects the position that 'disability' is a valued (but not sole) part of a person's identity and that 'disabled' comes from a place of pride rather than shame. I also use the term 'impairment' to refer to the physiological condition of the body (I recognize this term is also both contested and contestable), and the term 'disability' to refer to the social, cultural and material factors that can mediate the experience of impairment.

Many disabled people continue to have their sexualities denied and/or ignored. Their sexual desires and practices are routinely cast as inappropriate and unnecessary through dominant sexual stereotypes which position them as asexual (as lacking any sexual feeling and desire) and/or sexually inadequate. Alternatively, disabled people may be stereotyped as sexual victims and/or objects of fetish: the assumption that their only experience of sexual life is through sexual violence and abuse, or through contact with 'devotees' (individuals who are specifically attracted to disability and/or impairment).

In contrast, disabled people can be stereotyped as sexually 'deviant' or 'hypersexual'. This may be through having 'facilitated sex', where a disabled person receives support from a carer or personal assistant within sexual life, but also through more conventional means such as purchasing sex from a sex worker ( a "prostitute"). These alternative forms of sexuality are considered deviant because they further contradict wider stereotypes of disabled people as passive, vulnerable and childlike. Most of all, they challenge the common notion that disabled people aren't supposed to be having or desiring sex at all.

### **The research sought to explore three areas:**

- The wide-ranging means through which disabled people experience sexual life, opportunities, encounters, identity, and their sexual and intimate relationships with others.
- The strategies that disabled people may employ in order to manage and negotiate their sexual and intimate lives, particularly in the context of sexual stereotypes.
- The psycho-emotional impact of sexual stereotyping and the psycho-emotional consequences of disabled peoples' own strategies of management.

## What was the context for the research?

The research was sociological and ground in an interpretive research paradigm which viewed sexuality, gender, impairment and disability through a critical disability studies lens (see box 1). Interpretive research traditionally seeks to explore social phenomena through collecting 'qualitative' data which is data in the form of words rather than numbers or statistics. Qualitative research doesn't attempt to quantify or measure peoples' experiences; instead, it typically privileges depth (over breadth) and meaning (the 'why' over the 'how'), and so can offer meaningful insight into the social world and peoples' experiences. Therefore, the aim of this research was to gain an in-depth understanding of disabled peoples' experiences through exploring, listening to, and interpreting their own sexual stories.

### Box 1.

- **Critical disability studies fundamentally challenge the 'personal tragedy' or medical models of disability, and contest ableism and ableist society.**
- **Ableism can be described as a network of beliefs and structures in society and through which 'able-bodiedness' is privileged as the normal, natural, and desired bodily state. In ableist society, disability and impairment are cast only as inferior, defective and less than human; therefore disabled people must strive to become 'normal'.**

## What did I do?

### Research Advisory Group

A Research Advisory Group made up of disabled people was established to guide the research, offer expert knowledge, and ensure that the research process was accessible, engaging and empowering for those who took part. The 'group' took both physical and virtual forms. For example, some local disabled people attended a core group while people who lived further away were regularly consulted via email and Skype. The group was an important aspect of the research because it placed disabled peoples' voices, knowledge and experiences at its core. It also worked to ensure that research outcomes were as accessible and meaningful as possible and could transfer to the reality of disabled peoples' everyday lives.

## Recruiting Participants

Finding individuals to take part in the research took various routes. For example, some people were recruited through feature articles or advertisements in popular disability press. Others were recruited through advertisements posted on the 'online forums' or 'chat spaces' within the websites of a range of charities and organisations. The purpose was to gain a varied sample, consisting of participants with different impairments, genders, ethnicities, socio-economic backgrounds, sexual orientations, and impairment types (see box 2). While the sample ideally would have attracted more people from minority ethnic backgrounds and of different sexual orientations, it did contain a wide variety of participants from many different walks of life which produced a diverse collection of sexual stories.



Photo: Recruiting participants through disability press

### Box 2. Participants...

- 25 disabled people and 1 non-disabled partner took part in the research.
- Most participants were physically and/or sensory impaired, and had acquired or congenital (from birth) impairments of a wide range of 'severities'.
- More men than women took part, and ages ranged between 20 - 64.
- Participants were predominantly 'White British' and identified as heterosexual.

## Interpreting Sexual Stories...

Importantly, participants could choose the way in which they told their sexual stories. Some participated in a research interview, which could take place through a variety of different means (e.g. in person; Skype; MSN; telephone; email). Some others chose to write their sexual story through keeping a journal. Many made these choices based on preference rather than because of an accessibility requirement, showing that more traditional research methods and processes may benefit from considering the experience from a participant's perspective. The topics covered were things such as body image and identity; childhood, puberty and adolescence; previous and current relationships; formal and informal caring and support; finding partner/s; and sexual desires, pleasures and practices. Following data collection, data was transcribed, coded ('organised'), and analysed.



## Key Findings

### 1. Disabled men and women were significantly disempowered by sexual norms.

In society, 'good' and 'successful' heterosexual sex is narrowly defined; for example, as penetrative; spontaneous; and mutually pleasurable at the same time (e.g. that partners orgasm together). Also common, is that both our bodies and the sex we have should look like a Hollywood sex scene. Our gender roles must also not stray from the perceived 'norm'. For example, 'real' men should be sexually dominating, impulsive and have an insatiable desire for sex in order to be perceived as masculine. In order to be perceived as feminine, women should look sexy and alluring whilst being coy, sexually passive and willing to facilitate male desire. These 'sexual norms' are deep-rooted in media, culture and science. While these sexual norms can be problematic and restrictive for *all* people, they can be particularly problematic for disabled people whose bodies may sit further away from this 'ideal'.

Overall, participants upheld these sexual norms as 'natural' and 'fixed' (as most of us do) which impacted considerably on their experiences of sexual opportunities, identities, and intimate relationships. Many said they felt sexually inadequate – a sexual failure – and reported feeling pressured and frustrated at not being able to 'achieve' this form of sexuality. In fact, the feeling of failing to 'achieve' or 'maintain' this form of

sexuality was as oppressive for many participants as the routine sexual stereotypes cast upon disabled people. What is more, many participants regularly engaged in innovative and novel sexual practices which both challenged and expanded these restrictive sexual norms (and brought them considerable pleasure). However, because these practices and pleasures differed to the norm, participants felt ashamed of them and defined them as abnormal.

## **2. Disabled men could exercise more sexual power, and had better sexual access and opportunity, than disabled women.**

In society, men generally hold more social and sexual power than women, and many disabled male participants were not excluded from this in relation to their sexual identities and practices. For example, most disabled male participants had more positive body images than disabled female participants, or if not, could work on their bodily esteem to self-acceptance. Many disabled men in the sample could also negotiate a more empowering sexual role; for example, where their bodies restricted them from taking part in penetrative sex, they could learn to excel at other sexual practices (e.g. oral sex) and build a positive sexual identity based upon these abilities. Additionally, disabled men had access to sex through ‘alternative’ means such as facilitated sex and through paying for sex. In contrast, many disabled female participants experienced significant bodily self-hatred which couldn’t easily be resolved. The majority of disabled women also didn’t have the esteem or confidence to negotiate their desired role in sex, which many said was to be more active and experimental. Most had little or no access to facilitated sex or the option to pay for sex; either these options weren’t easily available to disabled women, or women felt they couldn’t explore them for fear that it was ‘unfeminine’. However, while male participants often had far better access to arrangements where sex could be paid for via a sex worker, these arrangements seldom provided long-term intimacy, closeness, and affirmation for disabled men; many of whom were left dissatisfied and unfulfilled following these activities.

**Mark<sup>2</sup>: “[Paying for sex] It’s like being gutted, you just got sex and you actually want the whole package: A relationship, sex and everything else.”**

**Kadeem: “[Paying for sex] Relief for my cock, mind and heart feeling shit”**

**Robert: “My body is not Arnold Schwarz-thingies but I can live with that!”**

**Lucille: “My body – hideous, unattractive, un-toned, feeling – loss of any sensation. I HATE, HATE, HATE, my body.”**

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<sup>2</sup> All names are pseudonyms



These findings offer a powerful challenge to dominant ideas of male sexuality as more impacted by impairment and disability than female sexuality. They also show the overlaps between disabled and non-disabled heterosexual men and women's experiences of sex and gender. Most importantly, is that these findings show the real need to include gender when thinking about disability and sex to ensure that the sexualities and experiences of disabled women are not overlooked or considered of lesser importance.

### **3. Disabled men and women had to carry out forms of work within a variety of spaces in their private and intimate lives.**

Disabled participants regularly took on the roles of teacher, negotiator, manager, mediator, performer, educator, and resistor through a wide variety of strategies. Much of this work took place within social interactions with others; for example, with partners, personal assistants (PAs), peers, friends, health professionals, strangers, teachers, families, sex workers, bullies, fellow activists, and prospective partners. For example, types of work included:

- Working to (re)claim a sexual identity in the public sphere; for example, among friends, peers and personal assistants.
- Devising strategies within sexual life to manage the bodily realities of impairment.
- Managing non-disabled voyeurism within social interactions and spaces. For example, negotiating non-disabled peoples' curiosity or intrusive questioning about sexual life and sexual 'capabilities'.
- Negotiating the routine lack of privacy experienced in a variety of areas which inhibited sexual exploration; for example, through personal assistants and family carers.
- Carrying out significant 'emotional work', the act of showing emotions on the surface that we're not feeling inside, within intimate relationships and when receiving of care from partners and personal assistants.
- Negotiating suitable sexual health and pregnancy care with health professionals.
- Survival work to endure multiple forms of abuse; but also the work to hide abuse from the outside world.

Recognising and labelling these forms of work is important. Firstly, it shows that disabled people have sexual agency and are skillful managers within their intimate and sexual lives. More broadly, it challenges some of the negative perceptions of disabled people (for example, as unproductive, worthless and lacking ability) and provides a fuller, more accurate description of the ways in which disability and impairment may be experienced.

**Hannah: “A lot of friends will ask, “Does Shaun’s willy work?”**

**Pete: “I’d ask for doors to be locked while I was showering. It never was locked... the door was always wide open.”**

**4. Impairment was important.** Impairment was foremost in participants’ minds when it came to physical sexuality, sexual pleasure and their sexual identity. Bodily factors such as fatigue, immobility, pain, scarring, and incontinence could have significant impact upon the ability to engage in sexual encounters and enact desired sexual roles. However, some participants devised strategies to manage these bodily factors which, although took work (see above), ensured that their bodies could be sites of sexual pleasure and enjoyment. These participants talked about their sexual pleasure freely; and without the shame that cultural messages about disability and sex can produce.

**Rhona: “Sex was brilliant, and we both enjoyed each other immensely: Intimacy, proximity, sensations, comedy, lack of control, feeling desired, being treated roughly and not as though I might break.”**

Additionally, other participants said that their impairments brought them ‘extra’ pleasure during sex, challenging society’s ideas about what constitutes a ‘sexy body’.

**Hannah: “I think you could get to the stage of having an orgasm through touching above the injury, which is amazing really.”**

**5. Disabled participants experienced substantial sexual oppression and psycho-emotional disablism as routine within their sexual and intimate lives.**

Psychoemotional disablism is a type of disablism whereby the outside world affects our psycho-emotional wellbeing – how we feel on the inside. Significantly, participants reported being bullied, abused, manipulated, exploited, chastised, ridiculed, humiliated and shamed in a variety of spaces within their intimate and sexual lives. This constituted substantial sexual oppression. Such treatment was often perpetrated by people in disabled participants’ own networks such as partners, friends, and families, as well as by strangers. Young disabled participants experienced sizeable exclusion during adolescence and said they experienced sexual bullying (bullying which made their assumed asexuality a target).

**Kadeem: “Family members made comments like “we pray you get better so you can get married and have kids”... that broke my heart.”**

**Pete: “Well, I have been asked if my wife was my sister. I've been asked if my kids are really mine. I have been asked if my wife & I needed IVF to get our kids. And I have been asked if I needed Viagra. All these things are very much a punch in the gut to masculinity.”**

Many participants were denied autonomy, agency and sexual freedom through their engagement with particular social institutions; for example, inadequate sex education, inhibiting care systems and unhelpful healthcare practitioners and services. This shows that disabled peoples’ sexualities remain very much a product of social environment and that these institutions can bring about feelings of failure and shame.

**Terry: “I didn’t think I was going to have sex, so it was quite an upsetting time, and there was a major point in adolescence where I did contemplate committing suicide because I didn’t think I’d ever develop into an adult where I’d have all the experiences of non-disabled people.”**

Moreover, many participants devalued themselves because of their disability, and some were devalued by their partners. Many felt that their partners ‘deserved better’. Others lived with an abusive partner or stayed in an unfulfilling relationship for multiple reasons related to their disability: because they didn’t believe they deserved any better; because they thought having a partner made them seem more ‘normal’ to the outside world; or for fear that they wouldn’t be able to find another partner who would accept their disability. This finding underlines the extent of work to be done to bring about sexual equality for disabled people, but also their right not to experience harm within their sexual and intimate lives.

## **Where to go from here?**

This research has provided just a snapshot of disabled participants’ experiences of sexual and intimate life. While these findings are not generalisable or representative of *all* disabled peoples’ experiences, they do offer a meaningful understanding of some of the complexities of disability, gender and sexuality, and the wider implications of these for disabled people. More than anything, I hope that this research has shown the value of listening to disabled peoples’ own sexual stories.

Further research is needed to explore disability and sexuality generally, but also within particular areas such as sex and personal assistance, and the experiences of lesbian, gay, bisexual and transgendered disabled people. This research has highlighted the specific

need for further research into the unique ways in which women with disabilities experience sexuality and intimacy. In addition to further research, findings also emphasise the need for more awareness and education surrounding disability and sexuality, in a variety of different spaces and institutions.

As stated on page two of this Research Summary, an important body of work now begins to ensure that disabled people, their allies, and organisations have access to these research findings – of which this Research Summary is just one part. If you have any ideas of networks or spaces where this can be accomplished, or would like any further information, please don't hesitate to get in touch.