

Chapter Ten: Sex and disability

The disabled body confronts how we might think ethically about the relationship between crime, sex and desire. Part of this confrontation stems from the paradoxical relationship between the **human rights** that a person with disabilities has, and the ethics of how they are practiced. This chapter will explore the issues at stake when we discuss sex and disability from a criminological perspective. Although we are yet to establish a comprehensive criminology of disability and **sexuality**, there is an emerging body of work from disabilities studies which can help criminologists develop a better understanding of this topic.

By the end of this chapter you will understand more about:

- The ethical issues at stake when analysing disability and its intersection with **sexual practice**.
- How issues of consent and capacity influence approaches to sex and disability in different criminological contexts.
- The diverse theoretical approaches we might adopt when studying disability.
- How disability intersects with **gender, 'race', sexuality, ethnicity, class,** and age.

The contested sexual politics of people with disabilities pose a unique challenge to our study of sex and crime. In this chapter we will be uncovering some of the ways that approaches to sex and disability can help us to understand how crime and **deviance**

are constructed, and to recognise some awkward truths that we have to face when we encounter the disabled body in the context of sex and crime. As Raymond J. Aguilera (2000: 259), citing poet Mark O'Brien points out, unless we die first, we and everyone we know will eventually become disabled, so issues which address the rights of people with disabilities before the law are pertinent for us all. It is for this reason that in this chapter we refer to people with no disability as being 'temporary-abled'.

People who are disabled are, to a certain extent, especially at risk of sexual violence. Like anyone, they are at risk of abuse and harassment, and they are also susceptible to having their voices silenced when it comes to expressing their own autonomy such as when making decisions about contraception, whether to have a baby, or to continue with a pregnancy. Alongside this, separate debates about the right of people with disability to have sex are intertwined with debates about **sex work**, sexual surrogacy, and whether institutions should intervene in sexual relationships between consenting adults where at least one partner has a disability.

All of these elements are why the intersection of sex and disability is a field ripe for criminological enquiry. We cannot cover all the issues at play in this chapter, so we will instead consider four cases; recalling our discussions in Chapter Four, we will explore what consent looks like for people with intellectual disabilities; what dating whilst disabled is like; what disabled desire means; and what the implications of this are for people living in institutions, particularly adults with dementia.

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Spend some time reading and thinking about the following lines written by poet Mark O'Brien (1987), who lived most of his life inside an iron lung:

Love poem to no-one in particular

let me touch you with my words

for my hands lie limp as empty gloves

let my words stroke your hair

slide down your back

and tickle your belly

for my hands, light and free flying as bricks

ignore my wishes and stubbornly refuse to carry out my quietest desires

let my words enter your mind

bearing torches

admit them willingly into your being

so they may caress you gently

within

- What picture does the poem paint about disabled sexuality?
- Does anything about the themes evoked in the poem surprise you?

- Notice any other thoughts, feelings, or impressions that this text arouses in you, as they may help you reflect on your own responses to the issues that we encounter in this chapter.

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Socio-political context

The rising influence of medical **discourses** at the beginning of the twentieth century in the **Global North** saw people with disabilities segregated into long-term stay hospitals where they were infantilised and denied civil liberties. In response to this, a body of critical disability activist work has emerged. In particular, over the past 25 years, disability scholars have been hugely significant in terms of establishing the rights of people with disabilities to establish sexual citizenship (Shakespeare et al, 1996; Davies, 2000a, b; Aguilera, 2000; Shildrick, 2007; Shakespeare and Richardson, 2018).

The concept of sexual citizenship describes the politicising of the erotic, of desire, and of sexual practice. Often used to describe **LGBT+** people's rights to express their sexuality, this understanding of citizenship, forged following a human rights-based agenda, recognises that people have rights to access certain sorts of spaces from which they might have historically been excluded, such as for instance, bars and clubs, the House of Commons, the street at night time (Bell and Binnie, 2000; Puwar, 2004, Stanko, 1990). Sexual citizenship is also about asserting institutional rights for all

people; the right to a family or to get married, the right to be recognised as a romantic partner in the eyes of the law, or within medical discourses (Barker, 2013; Ryan-Flood, 2009). Sexual citizenship is also about having the freedom to express your sexual desires where those desires have historically been considered to be paraphilias (for example, BDSM – bondage, domination, submission, sadomasochism, see our discussion in Chapter 9) and the right to have control over your body; the right to choose contraception, the right to an abortion, the right to have sex reassignment surgery, or not (Richardson, 2015). In this respect, disability studies, like LGBT+ activism share a number of political priorities, and the interplay and points of connection between queer theory and ‘crip’ theory, which we encountered in Chapter Two, is one that is helpful to reflect upon.

The claim for people with disabilities to enjoy full sexual citizenship is a pertinent one. However, it is only in recent decades that this has emerged. Certainly, in the twentieth century there were concerns about preserving ‘good stock’ within the population and of preventing the reproduction of bodies which were somehow considered to be deficient. Current concerns about sexuality can be understood as an expression of the **paternalistic** attitude a temporary-abled majority have about people with disabilities. In some mainstream discourses, people with disabilities have been considered to have no sexuality – to be sexless – or to be out of control and hyper-sexual. Shildrick (2007: 56-7) notes that the sexual expression of people with disabilities has been silenced. Children who are disabled are excluded from sex education classes because it is

assumed that they will never be sexually active. Elsewhere, young women with intellectual disabilities (ID) are non-consensually sterilised by their families to avoid pregnancy (Chou and Lu, 2011), whilst sexually active people with disabilities, or those who are just interested in sex are shamed (Abbott, 2013) and parents who have disabilities have been pathologised (Morris, 1991, Shakespeare et al, 1996).

Treating people with disabilities so differently to temporary-abled people is obviously problematic in the context of sexual citizenship. And yet disability brings with it some tangible challenges that we must take seriously if we are concerned with justice more broadly. We are going to explore some of these in this chapter. The notion of sexual citizenship itself has been critiqued by Diane Richardson (2015) for its '**Western-centric**' focus which is rooted within a neo-liberal understanding of human rights-based discourses (see Chapter Seven for our discussion of human rights). We will explore some of the implications of this too.

Understanding disability

In England and Wales, disability is defined in section 6 of the Equality Act 2010 as 'having a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities'. 'Substantial' means something more than minor or trivial, for instance it takes much longer than it usually would to complete a daily task like getting dressed, whilst 'long-term' means lasting for 12 months or more.

The Americans with Disabilities Act 1990, defines a disabled person as: 'a person who has a physical or mental impairment that substantially limits one or more major life activity'.

Adopting a more bio-psychosocial approach, in 2011, the World Health Organisation (WHO) established that disability was something that resulted from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

This notion of 'impairment' when talking about disability marks a significant shift in contemporary thinking about disability. Impairment is the language used to describe the condition pertaining to the person with the disability. The disability is not attributed to the body of the person themselves (Oliver 2012; Bunt, 2018). You will note that the USA definition, and to a certain extent the British definition, situates disability as something that 'a person has', whilst in the WHO context, the impairment is something that a person encounters by interacting with a world that does not treat them equally. This way, a disability is not a personal attribute, but rather the outcome of inequitable social interactions.

Models of disability

These different ways of thinking about disability are called models. It is helpful to understand these different models and to reflect on the ways that they interact with issues related to crime, deviance and sexuality, however, given the diversity of types of disability that exist and the different ways in which they present themselves, we often find that thinking about disability solely through models is not always helpful.

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Table 10.1 outlines different models of disability.

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Consider each of these models carefully.

- Which do you think is the most convincing model?
- Which do you like least? Why do you think this is the case?
- Is there a better way to explain what we understand by 'disability'?

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The two most common and straightforward ways of thinking about disability are the bio-medical model and the social model. The bio-medical model of disability posits that a person's impairment is what causes their disability and that there is something wrong with their body or their mind which the medical realm might be able to fix, or

at least manage. The bio-medical model focuses on the individual and attempts to fix or to cure them.

On the other hand, the social model posits that people are disabled by a world or a social life that is not equipped for them and which puts barriers in the way of their capacity to flourish to their fullest. The development of the social model of disability is hugely important in terms of moving policy affecting people with disabilities forward, and of moving beyond a 'pity model' in which people with disabilities were considered to be simply unfortunate victims of their affliction. Instead, it focuses on the collective rights of people with disabilities and their exclusion from society. Society caters to the needs of temporary-abled people and neglects the differing needs that different people have for accessing spaces, goods, and services.

By placing the emphasis on the social and moving away from the emphasis on the individual, disability activism was able to mobilise for changes in attitude at a cultural and social level. As well as a model, this social perspective formed the basis of a movement in the 1970s started by activist Paul Hunt. Members of Union of the Physically Impaired Against Segregation (UPIAS) wanted to steer away from an individualising bio-medical understanding of disability towards one which challenged forms of prejudice, discrimination, and inaccessibility in the built environment.

The advances made by a social model of understanding disability are inflected by a critique mobilised by the critical realist and embodied perspectives which are articulated by Roy Bhaskar and Berth Danermark (2006), Christopher Frauenberger (2015), Bill Hughes and Kevin Paterson (1997) and Paterson and Hughes (1999). From these perspectives, the social model's erasure of the embodied has been called into question (Shakespeare and Watson, 2001). From a critical realist perspective, the experience of disability is composed of a multiplicity of factors, and the way to understand disability is to attend to the different elements that compose disability. This involves, according to Bhaskar and Danermark (2006: 288-9) taking into consideration the biological experience of an impairment alongside the social and cultural effects, or interpretations of, an impairment. It also means thinking about what each disability might mean economically, institutionally, and psychologically for the person in question and local, meso, or global scales. This multi-layered analysis is what they refer to as a 'necessarily laminated system', where the levels and context and scales begin to create an impression of what being disabled means. For Sarah Bunt (2018: 190-1) this type of multi-layered analysis of disability helps to explain the complex relationship people have with disability, including, for instance, having a positive attitude to a disability, whilst also not wanting to normalise disability.

According to Shildrick (2007: 58) and Hughes and Paterson (1997: 328) the disappearance of the body in disability theory – a consequence perhaps of crip theory's engagement with post-structuralism and queer theory – undermines the

claims that people with disabilities make for sexual citizenship. It becomes a way of thinking that is complicit with erasure of people with disabilities as sexual citizens. The material reality of the body which feels constant pain, which cannot walk, which hears badly, which struggles to remember information, or which is amputated, has to be accommodated in discussions of sexual rights. As Jenny Morris (1991) writes, though the accident which means that she now uses a wheelchair has taken her on interesting and rewarding paths during her life, she would also have the function back in her legs back if she had the chance to. As she says, her experience of her disability is attenuated by the fact that she was an adult when she had her accident. Moreover, her ethnicity and her class provided her with material and social advantages when navigating the world as a wheel-chair-using mother of a young child. Such advantage would not necessarily have been available to differently marginalised people with disabilities who may have experienced different forms of prejudice or harassment as parents who were disabled (Morris, 1991; and see also Goodley et al, 2018). The body matters. Indeed, Hughes and Paterson (1997) suggest that a phenomenological approach helps us to understand the body as something which has its own experiences, that is lived in, that feels. What they call the 'sociology of impairment' becomes a way to take the body seriously in disability studies even if it is also true that social barriers also compound sexual social injustice for people with disabilities.

The diversity of the disabled experience is inflected by positionality and intersectionality – class, age, 'race', sexuality, gender – as Morris notes. Yet it is also

diverse as a category. When we talk about disability there are a huge range of conditions and impairments that we may talk about; consider the difference between being Deaf and being reliant on using a wheelchair. And even within similar categories of disability – intellectual disability, for instance – there are different manifestations and severities of disability. This diversity means that when it comes to sexuality, there are issues and ethics that will not be relevant for everyone with a disability, and certainly will not be relevant in the same way.

Disabled sex and criminology

As social scientists are starting to research more about disability and sexuality, there is a lot of emerging work that helps us in our study of criminology and **deviance**; particularly surrounding questions of consent, capacity and desire.

Intellectual disabilities (ID)

People with ID are arguably more at risk of sexual violence than many other people with disabilities because their lives are more likely to be governed and managed by carers. This **governance** inhibits their opportunities to exercise consent and to develop the capacity to withdraw it. This is particularly pertinent when considering issues related to pregnancy, contraception, and intimate relationships.

Scholars agree that the expression of sexual desire forms part of the fundamental functioning of human lives (Tamas et al, 2019; Gil-Llario et al, 2018; Kramers-Olen,

2016; Abbott, 2013). That this is so loudly espoused in so many texts about the sexuality of people with ID speaks to the fact that this remains a notion that must be reaffirmed, rather than something which is routinely taken for granted as it might be for other people who are not disabled in this way.

As the work of Angus Lam et al (2019), Maria D. Gil-Llario et al (2018), and David Abbott (2013), demonstrate, people with ID do desire to have sexual relationships and are, in no way, intrinsically sexless. Lam et al (2019) conducted a systematic review of studies to highlight the different ways in which people with ID have their sexuality policed, in spite of the fact that they are interested in, and desirous of, sexual relationships.

Some people report 'self-imposed abstinence', either because they found sex disgusting or otherwise undesirable because pregnancy and child-rearing – one of the potential consequences of sex – were considered to be things that they could not do. In other cases – and echoing the findings of Abbott (2013) – people with disabilities reported being prevented from entering into sexual relationships because of barriers put in place by their families or carers as part of safeguarding measures. Some participants reported that being gay as well as having an ID made developing intimate relationships even more difficult.

At the same time, Daniela Tamas et al's (2019) research with professionals who work with people with ID demonstrates that parents and carers tend to respond quite positively to the idea that people with ID would enjoy romantic or sexual relationships. They are nonetheless squeamish about how such a thing should take place. Tamas et al (2019: 252-4) report that parents in particular felt ill-equipped to educate their children about sex and worried that their children would express their sexuality in socially inappropriate ways and so they avoided discussing it with them. Care-workers and parents both reported more liberal attitudes towards supporting the sexual practice of men with ID than that of women, who were considered to be more at risk to abuse than men. This is borne out in Gil-Llario et al's (2018: 77-8) work with adults with ID who reported that even though they wanted to have sexual relationships (and indeed 84.2 per cent of their sample had had some sort of sexual relationship with another person), many were not using contraception appropriately (even though they also knew what it was) and were less likely to report experiences of abuse. This was particularly true for male victims. Though they were having sex, and knew about sex, in many cases support was not in place to facilitate this in a safe way.

Tlakale N. Phasha's (2009) study of teenagers with ID in South Africa echoes this finding. She identifies that even though young people with ID were more at risk than their temporary-abled counterparts to abuse, they were also more likely to be excluded from education programmes about sex, contraception, and HIV prevention education. According to Phasha (2009: 189), young people with ID are made more

vulnerable because they lack knowledge about what abuse is, they might find themselves in a dependent relationship with their abuser, and they might have a communication deficit which prevents them from articulating their experiences. Alongside this, perpetrators of sex crimes against people with ID might assume that their victims will not be taken seriously by a criminal justice system because of their disability, which might encourage this sort of abuse. Anne Kramers-Olen (2016: 507) adds that having little sex education, living in authoritarian institutions, and holding 'a general sense of powerlessness' compounds South African young people's vulnerability to sexual abuse. These views are confirmed in Gil-Lario et al's (2018) own study, which found that amongst their Spanish sample, all the men who reported that they had been sexually abused were blamed (by family or institutions) for the abuse that they had suffered.

For Phasha (2009), the circumstances of abuse are exacerbated by the specific South African context of her work. The abuse of people with ID is believed to be widespread and often takes place in the home. This is due, in part, to a misconception about a possible cure for ID; that ID is caused by 'bad blood' in the brain that can be cured through heavy bleeding (for instance the bleeding that occurs after childbirth) (Phasha, 2009: 194). This, coupled with a preference for dealing with abuse situations in private instead of through formally recognised external channels means that abuse, if it is detected, might often remain unpunished. Sometimes this is because punishing an offender might be detrimental to the rest of the family of the person with ID, in

cases where the perpetrator is also the breadwinner of the household (Phasha, 2009: 196). Sometimes, it is simply that the legacy of police violence seeded during the era of apartheid (a policy of racial segregation) means that **Black** South Africans in particular are reluctant to report criminal activity to the police (Phasha, 2009: 199). Or, it is the Ubuntu philosophy that guides responses to sexual abuse of people with ID, and which can be hard to recognise as punishment, through Western eyes. Ubuntu – a philosophy of caring and humanity within a community – offers collaborative, dialectic ways of resolving trouble which might be something akin to **restorative justice**. It is Ubuntu that informed Archbishop Desmond Tutu's Truth and Reconciliation Commissions in the aftermath of apartheid. It is Ubuntu which encourages 'reconciliation, restoration and harmony' (Phasha, 2009: 200) as opposed to punitive punishment and incarceration that is preferred in non-African contexts, including the Global North, when it comes to sex offenders. This can mean that it may look like no formal punishment has taken place when in fact, alternative solutions may be at play.

The influence of culture and society is just as significant when it comes to how sex and people with ID are encountered in the British (Wilkinson et al, 2015), Serbian (Tamas et al, 2019) and Hong Kong (Lam et al, 2019) contexts. Here, as indeed in the South African case, it is **heteronormativity** and notions of **hegemonic masculinity** which are obstacles to people with ID enjoying full sexual citizenship. The emphasis on people with disabilities being as 'normal as everyone else' in their desires (Wilkinson

et al, 2015) and the idea that they should be helped to have sex which is as 'normal as possible', might appear to be forward-thinking, but it necessarily rests on assumptions about what those norms should be. Namely, that they are **cis-gender**, heterosexual desires for monogamous sexual relationships. Verity J. Wilkinson et al (2015: 102) highlight how stigma about having an LGBT+ identity, either from caregivers or other people in institutional settings, discourages gay or **trans** men and women with ID from expressing themselves. Similar stories of the embarrassment of others in the face of LGBT+ relationships are told by Abbott's study participants (2013: 1082).

Beyond this, heteronormative scripts of romance also limit the sexual expression of men and women with ID. Think of men with ID who do not pursue sexual relationships with women because they cannot be a 'breadwinner' or women who count themselves out because they 'are not fit enough' to be mothers (Lam et al, 2019, 217); think of parents who are more accepting of men's expression of sexual desire than of women's (Tamas et al, 2019, 252); think of care givers who show sympathy to women who are sexually abused but who disbelieve men when they say they were raped (Gil-Llario, 2018: 76-7); think of women with ID who are subject to the violence of a non-consensual sterilisation in Taiwan, in a way that men are not (Chou and Lu, 2011). These are all examples of the way that heteronormativity saturates these debates and curtails the possibilities of people with disabilities to enjoy fuller sexual emancipation. Imagine, against this background, a person with ID who expresses a desire to have a sex change, or to participate in BDSM. How realistic is it that this

desire might be actualised? Does it matter if it is not? What do the courts say about how people with ID should be treated, when it comes to sex?

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Let us think about this in the context of two English cases cited by Martin Curtice et al (2012). Bear in mind that these are *civil* cases that are considering capacity of individuals, they are not criminal cases like those we have discussed in Chapter Four.

Sheffield City Council v E and S [2004] EWHC 2808 (Fam)

Here, E, a 21-year-old woman who allegedly functioned at the level of a 13-year-old, had formed a relationship that was abusive with S, a 37-year old-man with a substantial history of perpetrating sexually violent crimes. E planned to marry S and the court was asked to decide whether or not she had the capacity to make this decision, to understand the nature of the marriage contract and the responsibilities of marriage, and that she was able therefore to give consent.

The court held that the test to understand whether a person has the capacity to consent to marriage had to be low, meaning that their understanding about marriage did not need to be sophisticated or nuanced. This also meant that because sex and marriage usually accompany each other, the capacity to consent to sexual relations here would also be set at a low bar. The court had to be happy that E understood what

marriage was. It was not for them to decide whether or not it was acceptable for someone with ID to marry someone with a history of sex offending.

According to Munby J, 'the court is not concerned – has no jurisdiction – to consider whether it is in E's best interests to marry or not to marry S. The court is concerned with her capacity to marry, not with the wisdom of her marriage in general or her marriage to S in particular' (*Sheffield City Council v E and S* at 102).

As such, the court did not intervene to prevent E from exercising her desire to marry S.

Think:

- What principles are at play here?
- What political ideologies underpin Munby's judgement?
- Do you agree with it?
- Do you have any trouble with it?
- How can we connect the decision to theories such as hegemonic masculinity or heteronormativity?

***D Borough Council v AB* [2011] EWHC 101 COP**

The case of AB concerns a 41-year-old male with 'moderate' learning disabilities who entered into a sexual relationship with another man, known as 'K' with whom he lived under the supervision of the local authority. Alongside this, there were two instances

where AB had been reported to the police for inappropriate sexual conduct towards children.

On one occasion a young boy in a dentist's waiting area observed a man touching his groin, licking his lips and was then asked by the man for his name. The dentist's diary showed that AB was due for an appointment at that time.

On another occasion, two girls aged 9 and 10 stated that when travelling on a bus, a man (AB) had commented upon their physical appearance, touched their upper legs and then attempted to look up their skirts. The police were notified. A month later, these two girls were travelling on the bus once again, as was AB. The girls notified the bus driver who also notified the police. AB was then taken to the police station and questioned. However, the police decided that no further action should be taken against him.

The court was asked to decide whether AB lacked the capacity to enter into sexual relations with K. The local authority wanted the court to issue an order to prevent AB from having sex with K. Here, as with E above, the court had to decide whether AB had the capacity to consent, or if his impairment was too severe for him to have that capacity.

The court relied on previous **case law** (XCC v MB, NB, MAB (2006)), and on the fact that capacity to consent to sex requires a low bar of understanding and that all that was needed was 'sufficiently rudimentary knowledge of what the act comprises and its sexual nature' (*D Borough Council v AB* at 22). The judge set out a three-limbed test to establish what that awareness might entail. To be able to consent to sex, a person must understand:

1. The mechanics of the act.
2. That there are health risks involved, particularly the acquisition of sexually transmitted and sexually transmissible infections.
3. That sex between a man and a woman may result in the woman becoming pregnant.

Following psychiatric assessment, it was found that AB did not have sufficient knowledge about any of the three limbs of the test for heterosexual relations and did not understand limb two, which meant he was not able to consent to homosexual relations either. Finding AB unable to consent to sex, then, Judge Mostyn ruled that the local authority provide AB with sex education to enable him to develop the capacity to consent and then to review the case in 9 months.

Consider the following:

One thing you might note, and Mostyn highlights this too, is that the three-limbed consent test has different outcomes depending on the sexual act in question; oral and

anal sex have different implications here, as does masturbation. So, the test might find that the same person has the capacity to consent to some things, but not others.

- What are the implications for 'justice' here? What does 'justice' look like in these cases?
- And what do you think of the decision of the judge?
- Are the human rights of people like AB, K and the children who AB approaches sufficiently protected?

[END TEXTBOX]

Dating whilst disabled

Some of the issues that emerge in the case of AB are expressions of the barriers faced by people with disabilities when it comes to developing sexual citizenship and engaging in, or pursuing, sexual relationships. With the case of AB, we see a capacity to consent test which is focused on a **phallogentric**, heteronormative construction of sexuality. Alongside this, that the judgement suggested that AB needed sex education to better improve his understanding of consent demonstrates an ongoing barrier that people with disabilities encounter. As Cassandra Loeser et al (2018) have demonstrated, they are excluded from sex education and not helped to achieve full sexual citizenship including the ability to advocate for their own desires, and consent to sex. That an issue like this should have to be resolved within the justice system demonstrates how acute this problem is, and points to the challenges of understanding consent across society. We saw some of this in Chapter Four.

Carol A. Howland and Diana H. Rintala (2001) have examined the dating behaviours of 31 women with disabilities in the USA in order to better understand the barriers that they encountered to dating. What they found was that women with disabilities started dating at an older age compared to temporary-abled women; if they were attracted to people when they were younger, their parents or carers limited their dating opportunities – perhaps out of a paternalistic desire to protect them – which meant that as adults they were much less experienced or knowledgeable about dating than temporary-abled women.

Internalising the notion that being disabled is a flaw, some women in the study reported that they dated people who were abusive or neglectful simply because they were the men who wanted to date them. A recent Public Health England (PHE) found that some women in abusive relationships were reluctant to report intimate partner violence and abuse because they had internalised the notion that their partners were 'saints' for putting up with them and that they would not be able to get a better partner; that they should be grateful to have someone. Some women with sensory impairments might also miss signifiers of abuse and may face barriers to leaving abusive relationships where their abuser was also their carer (PHE, 2015: 13-4).

On the other hand, some women with disabilities said that they were very selective about dating; some refused to date another person with disabilities because they felt

that it further marginalised them from the mainstream (Rowland and Rintala, 2001: 54). Some women felt that they are unable to advocate for themselves in relationships and were not able to say what they need, what they could and could not do, or how they felt. Or, if they do express their needs, they are ignored or not taken seriously by their partners.

The barriers to dating are also exacerbated by a 'genital-centric' understanding of sex (Loeser et al, 2018: 265). As O'Brien (1990), Tom Shakespeare et al (1996) and Shakespeare and Sarah Richardson (2018) demonstrate, preconceptions about what types of practices count as sex limit the spectrum of sexual practice that a disabled person might accommodate and silence or erase awareness of alternative practices that do not look like normative sexual practice such as sex with prosthetics, erotic massage, or masturbation. This is where the queer inflection of crip theory might also help (see Chapter Two).

The complexity of this is something that is explored elsewhere (Davies, 2000a, b). Dominic Davies proposes a sexuality and relationship facilitation project to help build the capacity of people with disabilities to enter into and negotiate intimate relationships. Emerging at the intersection between queer sexual identity and disabled identity this is a project which seeks to understand the ways in which sexual practice can be diverse, but also how different identities interact with the mainstream

ideas about sex in order to mobilise a critique to conventional understandings of sexual practice.

Through mobilising an 'ethics of care', Davies suggests that people with disabilities can be helped to develop their self-esteem and skills to ask for what they want when it comes to sex and intimacy. Adopting a **sex-positive** approach to facilitating sex for people with disabilities, as opposed to the squeamishness that we have already seen in this chapter, forms part of this framework. Davies' (2000b) project imagines that people with disabilities and their allies become trained facilitators in issues related to sexual practice, and that they learn, among other things, the practicalities of using barrier methods of contraception (such as condoms) if, for instance, they or their partner does not have good mobility in their hands. They might also learn about which sexual positions are best to accommodate people with different ranges of mobility, or how to use sex toys. With this knowledge, they might empower people with disabilities – and be empowered themselves – to have more rewarding sexual experiences and a fuller sense of sexual citizenship.

Dating and Sexual Consumption

This educational approach crosses over with the concept of sexual surrogacy. Sexual surrogacy is understood as a form of sex therapy where a therapist has sex with a client with disabilities in order to help the client better understand and express their sexuality or to deal with some past trauma or sexual difficulty. O'Brien's (1990) essay

about his experience with a sexual surrogate is certainly worth reading for the touching clarity with which he explains how sexual surrogacy profoundly helped him. O'Brien (2003) contracted polio at the age of six and spent the rest of his life living in an iron lung, which is a pressurised tank that helps to regulate breathing. His account of his relationship with his sexual surrogate outlines how this practice helped him, in his words, to become 'a human being'.

Yet, the concept of sexual surrogacy is controversial. Even amongst people with disabilities there is no consensus over whether or not sexual surrogacy is good idea (Shakespeare and Richardson, 2018; O'Brien, 1990), with some voices advocating it as a 'radical and sufficient' way for people with disabilities to establish sexual citizenship (Davies, 2000a: 184) and others criticizing it is a patronising 'poor substitute' for building interpersonal relationships (Shakespeare and Richardson, 2018: 86).

The notion of independent living is fundamental to the actualisation of sexual citizenship. Independent living is described by Shildrick (2007: 58) as a 'mode of existence that is structured by personal choice and the self-administration of welfare benefits'. Independent living allowances are offered to people with disabilities to help them manage their own lives, and can be spent on anything, which includes being used for sexual support services, whether this is therapy, sex work, pornography, or anything else. Do you think that this sort of sex work or sex therapy should be offered to people with disabilities? And if it should be, who do you think should pay for it?

Should it form part of the care packages that local authorities provide to people with disabilities who are living in their care?

[START TEXTBOX]

Consider the following scenarios that Shildrick (2007: 60) outlines and place them on a scale of what you think is acceptable and right, and where you draw the line, and why:

- Is it acceptable for a care giver to be expected to help a person with disabilities get ready for a sexual encounter either by helping them to undress or to wash before sex? What about afterwards? Is it acceptable for a care giver or personal assistant to help with masturbation if a person with disabilities needed help with this?
- Would it be right to expect a care giver to contact a sex-worker on behalf of a person with disabilities and arrange a meeting for them, or accompany them to a brothel?
- Should a care giver be expected to procure pornography for a person with disabilities?
- Should a care giver be expected to help move a person into different sexual positions?
- What if the person's desire is for sexual practice which deviates from the mainstream? Should a care giver be expected to accompany their client to a sex club, or a dominatrix, or a fetish club?

When thinking about sexual citizenship, and the rights that humans have to sexual citizenship, these questions, and our reactions to these questions, help us to see how rights might play out.

[END TEXTBOX]

Shildrick highlights how, within a male homosexual context, sex which does not happen in private might fall foul of the law if a third-party facilitator is required to assist in the sexual encounter (2007: 61). Once more, as we saw in Abbott's (2013) account of homosexual men with ID, the heteronormativity of the criminal justice system – and of institutions in general – penalises people who do not conform to the heterosexual mainstream. And what about the rights of carers or personal assistants? What if their desires come into conflict with those of their clients, for religious, cultural, or personal reasons? Once more, whether we adopt a right-based approach, a queer perspective, or we adopt the social model of disability to understand sexual expression, the answers and the ethics are not easy to untangle.

Desiring disabled bodies

Ethical conundrums arguably become more complex when we consider them in the context of what Richard Bruno (1997) refers to as 'devotees, pretenders, and wannabees'. Recently there has been a rise in online dating services for people who have disabilities, and for people who, disabled or not, want to date a person with disabilities. In 2012, the British Channel 4 TV show *The Undateables* brought disabled

dating to the mainstream. Despite the provocative title, shows like *The Undateables* are endorsed for the apparent sex-positivity by sites such as disabilitymatches.com. In spite of this, this increased visibility has not been met with enthusiasm by everyone. Some critics with disabilities have likened it to a 'freak show' or 'wildlife documentary' (Shakespeare and Richardson 2018; 88).

In 1997, polio doctor and clinical psychologist, Bruno initiated an exploratory study of the phenomenon that he, building on the sexologist John Money's work on apotemnophilia (love of amputation), referred to as 'devoteeism'. Devotees are 'non-disabled [temporary-abled] people who are... attracted to people with disabilities...especially amputees' (Bruno, 1997: 243). Bruno considers the case of the wife of a polio patient at his clinic who confessed in therapy that not only was she very aroused by the fact of her husband's walking impairment and the braces that he used to help him to walk, but she also pretended to have a disability herself when she had the occasion to. She would, for example, hire a wheelchair when on trips out of town and when she presented herself as a disabled person, she found this arousing (Bruno, 1997: 247). For Bruno, this woman was also what he termed a 'pretender'. Her paraphilia – non-normative sexual desire – as he called it, was attributed to neglect she experienced by her parents as a child and the tenderness she saw her parents demonstrate to another child with polio in her neighbourhood. For Bruno (1997: 258), such an attraction to people with disabilities is harmful because it cannot foster long-lasting and stable relationships. It is merely a sexual quick fix for the fetishist

(the devotee) and places an already seemingly vulnerable disabled person at even more risk.

Bruno's analysis has been critiqued and interrogated from a few perspectives (Sullivan, 2008; Aguilera, 2000). Bruno's analysis could be said to rest on the notion that any attraction to a disabled body is perverse and therefore inherently harmful. Its attribution to a story of childhood neglect further pathologises this as a form of desire (Sullivan; 2008: 185-6) and appears to erase autonomy on the part of people with disabilities, too.

Aguilera (2000) posits that devotee/disabled relationships might be empowering, as opposed to oppressive or manipulative. From a sex-positive perspective, he considers whether it might be possible to take at face-value the desire that devotees profess to have. This discussion echoes the approach adopted by Barbara F. W. Fiduccia (1999: 280) who asks why sex between a disabled and temporary-abled person is so taboo, and suggests that it is because of the 'childlike' status that people with disabilities are imagined to occupy in the mainstream. Thus, a squeamishness about desiring disabled bodies might be expression of paternalism. Per Solvang (2007: 52) suggests that devoteeism could be reconceptualised as a form of valorising disabled bodies in the same way that neurological conditions such as Tourette's syndrome have become associated with creativity and spatial thinking. Being desired by a devotee might be empowering. It might develop 'self-pride' and a 'positive attitude' in a disabled person

(Solvang, 2007: 61). Certainly, Solvang's (2007), Aguilera's (2000) and Fiduccia's (1999) analyses of this sort of desire allows for this possibility. However, it is hard to move out of the spectre of normativity.

As Solvang (2007: 62) highlights, it is often normatively beautiful women who have a disability who are thusly desired. Such a narrative plays out in Joseph Brennan's (2017) analysis of discourses about the athlete Oscar Pistorius's body on gay men's online forums who comment on his muscular body and who speculate on how easy it would be to rape him in prison because of his disability. Aguilera (2000: 260) notes that even though disabled bodies are now more visible as objects of desire, they are also often presented in specialist devotee publications and products (where a heterosexual male consumer is assumed), in positions of vulnerability, which entrench gender inequalities. Films or photographs of amputees, or wheelchair-using women boast that they show women 'transferring' into and out of their beds or wheelchairs, or putting on or taking off prosthetic limbs. The 2016 BBC 3 documentary *Meet the Devotees* told a similar story; there are people – devotees – who are drawn to disabled women, but it is the sight of them in positions of vulnerability or struggling to do things that people who are temporary-abled do not have trouble with (such as getting dressed or using the stairs) that is what they say they find most erotic.

The dominance of hegemonic ideas of beauty within these discourses means that even if devoteeism seems to subvert normative ideas about desire, there remains a risk that in some contexts it consolidates, rather than transgresses normative sexual expression. R. Amy Elman's (1997) discussion of disabled pornography also illustrates this difficulty. Drawing on some of the same case studies from Playboy magazine that Nikki Sullivan (2008) and Fiduccia (1999) also analyse, Elman criticises what she sees as the fetishisation of female immobility and the eroticisation of vulnerability (1997: 258) which entrenches **patriarchal**, heteronormative views of women. This, she argues, has implications for all women, not just those represented in pornography, or in films like *Boxing Helena* (1993) in which the protagonist, Helena, eventually has all her limbs amputated by a surgeon who is in love with her. These representations echo and resonate with women's experiences of sexualised violence in many, much more mundane contexts. Do you agree? Or do you think there might be something empowering that could be recuperated from these accounts of desire for a disabled body?

The ethical tensions that Bruno (1997: 244) outlines in his early paper become particularly thorny in the context of Bruno's third category of disability desirers; those who want to become disabled themselves. Unlike pretenders who want simply to appear disabled from time to time, a 'wannabe' wants to, for instance, have their leg amputated, or as correspondence analysed by Elman (1997: 262) suggests, 'become completely blind'. What is to be done about people who want to acquire a disability?

Who feel that they are a disabled person in a non-disabled person's body? Who have such a negative relationship with a part of their body, that they would rather remove it than live with it?

In order to address this question, we need to return to the concepts of consent and capacity. We also need to think, from an ethical perspective, about the body. To whom does a body belong? And can we do whatever we like with our bodies? What is the obligation of a medical professional to do what is perceived as permanent and irreversible damage to our bodies at our behest? Should the criminal law intervene in these matters?

[START TEXTBOX]

Read and reflect on the following case-study taken from Scotland in the UK.

'By taking my leg away that surgeon has made me complete'

In 1997, a surgeon named Robert Smith amputated the lower left leg of Kevin Wright. In 1999 he repeated the same operation on a German national named Hans Shraub. The men had separately consulted with him about the strong desire to remove this part of their body and the misery that their lives had become because they had to live with their legs. The legs were entirely healthy and did not cause the men physical pain. In an interview with *The Guardian* newspaper, Kevin Wright explained that he was in such despair about his leg that he had contemplated suicide. He continued: 'I just didn't want it. It didn't feel a part of me, I didn't understand why, but I knew I

didn't want my leg. I have happiness and contentment and life is so much more settled, so much easier'.

This form of surgery on a healthy leg – and the transforming of a person from temporary-abled to disabled – raises a number of ethical questions. The Falkirk hospital in question was subject to intense scrutiny and criticism for allowing this surgery to take place. Travis (2014) explains how a French national named Lily added to the story. Attempting to also have her healthy legs amputated, Lily travelled to Scotland in 2005 to seek the same surgery. Unable to persuade the hospital to amputate her legs, she set about destroying them so that they could be amputated. Using dry ice, she managed to damage her legs so much that an amputation was on the cards (Travis, 2014) only to be cancelled at the last minute to have Lily flown back to France un-amputated. She later managed, after a number of operations and infections to have her leg amputated in France; not electively, but as a result of there being nothing else to be done. After her leg was removed, she reportedly said that she was finally at peace.

The furore which the Falkirk case provoked did not lead to any criminal implications for surgeon Robert Smith, but the case was roundly condemned as 'unacceptable' by the chairman of the health trust in the area (The Herald, 7 February 2000) and the local Member of Parliament stated that he found it incredible that a surgeon would amputate a healthy limb (BBC News, 31 January 2000). And as we see in Lily's case,

the hospital would rather pay for a private medical plane to repatriate Lily than amputate her damaged leg.

- Why is there this backlash?
- If men and women are not incapacitated, and they are asking for this surgery, does preventing this become a 'suspension of their legal personhood' (Travis, 2014: 27)? And of their rights as people to make choices about their lives (Erin and Ost, 2007: 256)?
- The anguish, certainly, that Lily felt about her legs is palpable in Travis's (2014) account. Is her disorder something that should be cured with medical treatment (amputation)?
- Is there another solution that we should seek?

[END TEXTBOX]

Wright, Shraub and Lily had Body Integrity Identity Disorder (BIID) which is understood as a sort of reverse 'phantom limb' (Blanke et al 2009; Travis, 2014). It has been suggested that BIID is not unlike Gender Identity Disorder (a mismatch between gender identity and sex assigned at birth). It has also been suggested that BIID is the reasons why some people chose to have rhinoplasty surgeries, or breast reductions, or elective labiaplasties.

- Might this be the case? Is amputating a leg the same thing as having a nose-job?
- If not, why not?
- Is it like being trans?

- Is it the rightful place of the criminal law to intervene to prevent people from undergoing these surgeries?
- How does our answer change depending on the model of disability we apply to the problem?

Dementia, sex and navigating the institutional life

The final issue that we will think about is the issue of intimacy and dementia in an institutional setting. Dementia is a degenerative brain condition which can impair memory, moods, personality and other elements of cognitive functioning. People with dementia may live in institutional settings. Even up until the late stages of the diseases, people with dementia still have complex desires and needs, including the need or desire for intimacy or the building of intimate relationships.

Questions of capacity and consent that we have seen elsewhere in this chapter, alongside issues of autonomy and freedom that we have also discussed are salient here. The question is when, or whether, people working in a care home, or family members, should intervene in the sex lives of people with dementia.

Though there is more and more research emerging on sex in later life, there is still little guidance on how care workers and family members should approach the development of intimate relationships among people with dementia, where they occur (Rheume and Mitty, 2008; Di Napoli et al, 2013; Villar et al, 2014). Intimacy takes

many forms, of course, and as Chris Rheaume and Ethel Mitty (2008: 344) recognise, it is an ultimate expression of **agency**. Intimate feelings cannot be elicited from someone or received as intimacy if a person does not want them. This is why people's right to intimacy – the exercise of their sexual citizenship – is so important. In the context of people living with dementia, this is thought to have a positive effect on their wellbeing (Wiskerke and Manthorpe, 2019: 96). At the same time, people with dementia living in care homes do encounter barriers to their intimate relationships. In part, these barriers are socially constructed, inflected by norms of appropriate performances of masculinity and femininity, and by the dominance of heteronormativity which colours the world view of patients and carers of those living in care homes (Rheaume and Mitty, 2008; Di Napoli et al, 2013). Heteronormativity emphasises heterosexual relationships and also stigmatises non-normative relationships. Sex between older people, sex with people with dementia, and sex with people who may be married to someone else might fall in this non-normative category. Barriers are also imposed by the institution. The lack of privacy in a care home and the authoritative presence of the care workers can discourage intimate acts from taking place (Rheaume and Mitty, 2008).

A second issue that arises in the context of sexual relationships and dementia is the issue of consent and the capacity to consent to sexual practice. We have seen some of these debates play out in the context of people with ID. What about issues of consent relating to people whose capacities may fluctuate and degenerate as time passes?

What is the role of the law in these instances? How to assess the capacity to consent in circumstances where the impairment might be in flux?

We have already seen that in England and Wales the court adopts a low bar in the test to ascertain whether or not someone has the capacity to consent and is reluctant to intervene in this area of private life. Indeed, the MCA 2005 stipulates that the law cannot consent on behalf of someone else or intervene even if the person in question has consented to something that might be unwise or bad for them.

In a care home setting, the issue of adult safeguarding also comes to the fore in order to prevent abuse. As with other areas of disability work there appears to be a reticence amongst care home workers to give space to dementia patients to explore sexual intimacy because of the tendency to consider the 'recipient' of sexual attention or a sexual act as the 'victim' and the 'initiator' as the 'perpetrator' which leads care workers to adopt a risk averse attitude to managing sexual behaviour in a care home (Wiskeke and Manthrope, 2019: 99).

An additional concern is also an effect of the dementia itself. People with dementia may forget that they have had sex once it is finished. They may mistake other people for their partner. They may become sexually demanding in ways that are embarrassing/ distressing for other people. They may exhibit sexual disinhibition and behave in sexually inappropriate ways towards other people, by undressing

themselves in public, touching others without consent, or making suggestive comments to other people (Rheaume and Mitty, 2008; 347-8). In these instances, issues of consent are obvious concerns. There is also the risk of criminal justice involvement in cases where the disease has impaired their decision-making abilities. We must ask, is it in the best interests of a particular resident with dementia to intervene here? Alongside this, how else might we safeguard other residents living in a care home who may be on the receiving end of these advances? And what about the people who work in the care home: they are in charge of safeguarding, but what if they are also subject to this sexualised behaviour?

For Soren Holm (2001: 156), the capacity to consent should depend on the act in question, and not the type of person. So, a person may not have the capacity to consent to certain acts, but may be able to consent to more minor or more trivial ones. For instance, a person with dementia may lack the capacity to decide to follow a specific medical treatment, but they may still have the capacity to decide whether or not to get their hair cut, to have a bath, or to drink a whole bottle of wine. The imperative to act in the 'best interest' of people with dementia when it comes to making decisions on their behalf – proxy decision-making – rests on normative ethical values which may not be able to adequately take into consideration the authenticity of their desires. As with other areas which have a bearing on disability rights, education, training, and capacity-building are recommended for care-workers and family

members to better support the sexual practices of people with dementia. Yet the line between preventing abusive behaviour, the exercise of autonomy, and the capacity to consent is difficult to draw.

Summary

In this chapter we have looked at different areas of concern when thinking about the relationship between sex, disability, and crime. We have seen that there are several different theoretical models that can be applied to better understand disability. None of them alone is sufficient to capture the full complexity of disability. Alongside this, queer theory and sexual citizenship discourses help to outline the nature of the problem that criminologists must encounter when considering these issues.

We have seen that though consent, capacity, ethics, desire, and sexual practice are hugely complex, the law takes a light touch approach, adopting a capacity test that is set low. They do this so as to respect the agency of people with disabilities.

The more fundamental ethical problems posed to us by devotees and wannabes highlight the philosophical questions about the body that we have to take into account. They also highlight how the criminal justice system has, as yet, little to say about these issues despite their obvious relevance to criminology and questions of justice.

Finally, time and time again we have seen how it is education and awareness-raising that is offered as the solution to many of these complexities; education for people with ID about sex, consent, desire, and contraception, coupled with enabling communication across all parties that is not plagued by shame and embarrassment; education for care workers to help them approach sexual questions with people with dementia; education for family members of people with disabilities to help them understand how to approach this topic; education for people with disabilities about dating, sexual surrogacy, and advocating for their desires. As criminologists we have a part to play in this education, because we can bring our understanding of sexual citizenship, **social justice** and policing deviance to bear on these questions. What do you think that might look like?

Review Questions

- Is education the only way to improve sexual rights for people with disabilities? Are there any dangers in adopting this approach?
- Consider the different models of disability. Which one do you think is the most convincing? Which one are people most familiar with? Which is the most problematic?
- Think of words that you associate with sexual citizenship. Why do disability activists think that sexual citizenship is important? Do you agree?
- Is the emphasis on sexuality in disability studies misplaced? Should disability scholars be prioritising different things?

Other chapters that this links to:

Chapter Two (Theory)

Chapter Three (Sex and crime in time and space)

Chapter Four (Consent and its discontents)

Chapter Nine (Pleasurable Risk)

Chapter Twelve (Children, sexualisation and law)

Chapter Fifteen (How to change your life)