

## Disabled and Fighting for a Sex Life

How misperceptions about disability can prevent people with physical and cognitive impairments from being able to express their sexuality



Sofie Middernacht and Maarten Alexander/Mosaic

**KATHARINE QUARMBY**

MAR 11, 2015 | HEALTH

---

Like *The Atlantic*? Subscribe to [The Atlantic Daily](#), our free weekday email newsletter.

SIGN UP

---

Millie Dollar sashays onto the stage in a green, feathered dress to conclude the evening's entertainment with a sultry burlesque routine. The capacity audience at the ornate Epstein Theater in Liverpool is enraptured by her sensual beauty.

Burlesque, she says in [an interview](#), gives her a way of communicating through costume, routine and dance—which she does with panache. What the audience

can't see, though, is the hearing condition that means she must work hard to follow the beat during her glamorous routine.

A number of disabled performers have taken to the stage to entertain mainstream audiences in recent years, although in her routines, Dollar (unlike some) does not refer to either her hearing impairment or her depression, which she writes about with candor and insight.

The internationally famed multi-disciplinary performer Mat Fraser has long explored the relationship between disability, entertainment, and sexuality. He is currently appearing in the popular TV series *American Horror Story*. He said in a recent interview: "When you are disabled the two things people think you can't do are fight and have sex ... so I've got a black belt and I'm really good at shagging. The physical pleasures in life are really important to me."

---

**"When you are disabled, the two things people think you can't do are fight and have sex. So I've got a black belt and I'm really good at shagging."**

---

Research has shown that disabled people are less likely to have a long-term partner or marry than non-disabled people, although this is very dependent on impairment type. When a [2014 U.K. newspaper poll](#) asked people if they had ever had sex with someone who had a physical disability, 44 percent said "No, and I don't think I would."

So how can we shift the negative images of disability and sexuality that still dominate society's attitudes? Disabled people and their allies have been campaigning for change for decades. While it is not going to be easy, change is on the way, but with it comes new controversies.

\* \* \*

Disabled people's sexuality has been suppressed, exploited and, at times, destroyed over many centuries. It has been seen as suspect, set apart, and different from the

sexuality of non-disabled people.

**Tom Shakespeare**, a disabled academic, wrote *The Sexual Politics of Disability* nearly 20 years ago. It remains one of the few evidence-based studies in the field. “I think images of disability and sexuality either tend to be absent—disabled people being presented as asexual—or else perverse and hypersexual,” he says.

The key attitudes identified by Shakespeare appear as threads throughout myth and literature, from classical times onwards. Disabled characters and their sexuality appear relatively frequently in legends and texts, but are usually harnessed to powerful negative metaphors.

Consider the myth of Hephaestus, born “shriveled of foot” and cast out from Olympus by his mother. He is married off to the goddess Aphrodite, but she is unfaithful to him because of his impairment, which unmans him in her eyes, and he is cuckolded and scorned. This trope is repeated, much later, in D.H. Lawrence’s *Lady Chatterley’s Lover*, where Lady Chatterley satisfies herself with the virile gamekeeper because her husband is a “cripple.”

This scenario, where a disabled man is judged to have lost sexual power because of his impairment and his sexual partner has carte blanche to seek solace elsewhere, has become known as the “Chatterley Syndrome.”

As Shakespeare observes, disabled men (and, to a lesser extent, women) are rendered impotent and sexless by disability, and thus are seen as unattractive and vulnerable to mockery and exploitation. As Cicero wrote: “In deformity and bodily disfigurement, there is good material in making jokes.”

---

**In *Lady Chatterley’s Lover*, Lady Chatterley satisfies herself with the virile gamekeeper because her husband is a “cripple.”**

---

This may explain an assumption often made in the past—that it was better to shield disabled people from reaching out for sexual relationships, rather than risk the

potential of being rejected. There was an expectation that disabled people's sexual desires should be set aside and ignored, because they should not—or could not—be satisfied.

The second trope is that disability is a punishment wreaked for committing a sin and, as such, the disabled person is a wholly unsuitable sexual partner because they are evil and, paradoxically, powerful. One of the best examples is William Shakespeare's Richard III, who is written as twisted in body and mind or, as he says of himself, “rudely stamped” and rendered impotent by his physical limitations.

Disabled women have also faced this stigma. Many women with mental-health conditions—along with older people showing signs of dementia, and people with benign and cancerous growths—were caught up in the European witch-hunts of the 17th century, for example. One observer at the time, Reginald Scot (a justice of the peace in Kent, England), noted that they were “commonly old, lame, blear-eyed, pale, foul, full of wrinkles ... lean and deformed, showing melancholy in their faces, to the horror of all that see them.”

Disabled people have also been stereotyped as being hypersexual—a claim used against women with learning difficulties in particular. This has led on to persistent abuse of disabled women, particularly in institutions, where they have been routinely raped and abused for centuries. Early 19th-century whistle-blowers gave evidence of such maltreatment—which extended to rape and murder.

Another powerful archetype, Tom Shakespeare says, is the unconscious—and sometimes conscious—attitude surrounding reproductive fitness that suggests having a disabled partner is potentially contaminating, as it could pass the “problem” on to the next generation.

Disabled people have challenged this on many levels: For example, sexual relations are not all about procreation, not all impairments are inheritable, and many disabled people accept their impairment and the possibility that it might be passed on. Deaf (with a capital D) people, for example, consider deafness to be a culture, rather than an impairment, and believe it should be embraced and celebrated.

With eugenics—a now-discredited social philosophy—Francis Galton pursued the theory of contamination to its logical end. He argued, along with others who took up his ideas, that people with disabilities (along with the poor and the generally “unfit”) should be prevented from breeding.

The eugenics movement, which started in the U.K., was taken up with enthusiasm in the U.S. By 1914 nearly two-thirds of U.S. states had made it illegal for “feeble-minded” and “insane” people to marry. The so-called “Ugly Laws,” first passed in the 1880s, prohibited the “unsightly” from being seen on the street at all. Between 1907 and 1928, thousands of Americans were sterilised.

The legitimization of eugenic views throughout Europe and America ended in a logical, if horrifying, outcome: the systematic murder of thousands of disabled people in Germany after the Nazis came to power in 1933. By the end of World War II, it is estimated that some 200,000 people with disabilities had been murdered.

Asexual, hypersexual, perverse, and contaminated: These four damaging tropes from history combine to form a bitter legacy for disabled people.

\* \* \*

The disability movement first started to challenge those attitudes in the U.S. in the mid to late 1960s. The first disabled American war veterans were starting to arrive back from Vietnam and pushing for inclusion. Students were also key to this new civil-rights battle.

Ed Roberts was the first student with significant disabilities to attend the University of California, Berkeley. In the early 1960s, he and other disabled students formed a group, The Rolling Quads, to advocate for UC Berkeley to become the first truly accessible university. From that point onwards, British disability activists have looked to UC Berkeley, and to the U.S. more widely, for inspiration in the civil-rights struggle, including around the right to independent living.

Student activists wanted the right to have sex too. The University of California responded by founding a sexuality and disability center, where sex therapists could

give advice and facilitate contact with “sex surrogates,” as they became known. Although prostitution was outlawed in almost all U.S. states, the legal status of sexual surrogates was (and still is) undefined—meaning the sexual services they offer are technically neither legal nor illegal.

---

## **"My catheter was fitted so I could wear a bikini, but awkwardly positioned for having sex."**

---

Disabled writer Mark O'Brien studied English and journalism at UC Berkeley and was commissioned by a magazine to interview disabled people about their sex lives in the 1980s. This led him to explore his own sexuality. He [wrote in \*The Sun\* magazine](#): “I wanted to be loved ... held, caressed, and valued. But my self-hatred and fear were too intense. I doubted I deserved to be loved ... Most of the disabled people I knew in Berkeley were sexually active, including disabled people as deformed as I. But nothing ever happened.”

O'Brien eventually saw a sex surrogate, Cheryl Cohen Greene, and lost his virginity with her. They became life-long friends. Two films were made about him—the Oscar-winning short *Breathing Lessons* and *The Sessions*. He had five years of happiness with the writer Susan Fernbach before his death in 1999. Mark O'Brien's struggle to affirm his right to sexuality has become iconic in the wider campaign for sexual rights for disabled people.

\* \* \*

“Supporting disabled people to find partners and enjoy sex brings me endless joy and satisfaction,” writes Tuppy Owens, a sex therapist and the author of [Supporting Disabled People with Their Sexual Lives: A clear guide for health and social-care professionals](#).

She's campaigned for 20 years to boost disabled people's confidence and access to sexual services. Among other services, she runs the Sex and Disability helpline, the [TLC website](#) (which connects disabled people to sexual services), and the Outsiders

Club, a social club for disabled people looking to make friends and find partners. She also runs an online club for peer support and the Sexual Respect Toolkit website to support those who work in healthcare or social care to initiate conversations about sex.

The stories are genuinely moving. One woman used the help of a peer supporter to ask for her catheter to be re-sited. The woman is quoted: “My catheter was fitted so I could wear a bikini, but awkwardly positioned for having sex. When I pointed out to my consultant that I preferred sex to sunbathing, he said, ‘OK, let’s reposition it then.’ As a result, my husband and I have had a lot more fun!”

Owens’ book gives a sense of the vibrant emergent scene for disabled people, as well as providing practical advice about things such as sex toys suitable for people with different impairments. These include vibrating cushions, remotely controlled masturbation devices, and vibrators with long handles for people who could not otherwise reach.

---

**"When you see some of my clients, their prospects of getting a partner are limited, if not nil."**

---

Owens is one of many people across the world working to provide opportunities for disabled people who want to access sexual services. Rachel Wotton, a sex worker from Australia, is a founding member of [Touching Base](#), a charity that has connected sex workers to disabled people since 2000. Similar schemes have since been set up in Canada and in New Zealand.

Wotton mounts a strong defense of the sex industry and its role in providing services to some disabled people: “For some people with disabilities, they only have one life, and to wait around for society to say ‘I will date someone with cerebral palsy’—well, when you see some of my clients, their prospects of getting a partner are limited, if not nil,” she says. “If they choose to see me, that’s OK. Society should change its ways, too, but people with disabilities should have all the rights that people without disabilities have. It’s not an all-or-nothing thing.”

In some countries where legislation around sex work is permissive (e.g. Holland, Germany, Denmark, and Switzerland), there is a flexible attitude towards services for disabled people. In Holland, as in Denmark, social workers ask disabled clients whether they need any support with their sexuality and may even fund limited numbers of visits by sexual assistants or sex workers.

The pioneer of the continental “sexual assistant” model is a Dutch woman, Nina de Vries. In a Skype interview from her home in Potsdam, she explained how physically disabled people started asking her to give them erotic massages in the 1990s (she does not offer penetration or oral contact). This work grew and grew. Eventually De Vries was asked to speak about her work to the media and at conferences.

In 2003, the Swiss charity [Pro Infirmis](#) asked her to train a more formal network of sexual assistants in Zurich, triggering considerable resistance from religious groups and some disabled people. The charity drew back from the work, although another organization does now offer a similar service in Switzerland, and others are available in France. A rather clinical masturbation service called [White Hands](#) has been available to some disabled men in Japan since 2008.

De Vries now works with people with learning difficulties and dementia, although she readily admits there are concerns about capacity and consent. “I work with people who are not able to communicate verbally, but they can say a clear ‘no’ or ‘yes’ by using their body, sounds, or facial expressions.” She has turned down clients where she thinks that there is not a clear wish for her services.

---

**"I work with people who are not able to communicate verbally, but they can say a clear 'no' or 'yes' with sounds or facial expressions."**

---

In Australia, Touching Base works with dementia and disabled people’s organisations to develop consent guidelines. “There is a lot of discussion around



consent at the moment,” Wotton says. “In terms of dementia, we are looking at what people used to do, when they are losing capacity.”

“We talk a lot about informed consent, which is about understanding what you are consenting to, of your own free will. Our responsibility is to learn how people are communicating, whether it is with words, pictures or adaptive devices.”

\* \* \*

The fight for so-called sexual citizenship is not confined to the disability-rights movement. Campaigners demonstrate how sexual minorities are marginalized, denied equal access, and even criminalized in particular nations. But while there is a common aim for sexual rights to be seen as fundamental, the means are in dispute.

Perhaps surprisingly, there appears to be little about sexual citizenship and the wider questions it brings up in medical-ethics journals, although ethicists do explore the issues around disabled people’s access to paid sexual services.

The arguments include that because some people with disabilities cannot obtain sex without paying for it, they should be exempt from any penalties arising from prostitution—and that the state should even meet the costs. Others argue that sexual needs are not *de facto* a right and that, at best, volunteer organizations should meet people’s need to have sex. Examining the potential harms of prostitution, one ethicist concluded that there may be a narrow benefit towards granting a right towards sexual pleasure.

But where are the voices of disabled people themselves in this? In the words of disability activists, who first coined the phrase, “Nothing about us, without us.”

Some disabled people argue that the state should decriminalize sexual-assistance services for people who are not able to have sex independently, and even fund them to use these services. Others call for other forms of help, such as peer support on subjects like how to regain sexual confidence after acquiring an impairment. There is broad agreement that sex education should be more inclusive of disability. And

disabled people would like to challenge the negative attitudes that mean that they are not seen as valid sexual partners.

In 2005, the magazine *Disability Now* found that 37.6 percent of disabled men would consider paying for sex and that 16 percent of disabled women would do the same—although a minority in both genders, these figures are higher than those seen in the general population. However, a number of prominent disabled British and American activists profess themselves uncomfortable with the idea of paying for sex per se.

[Kirsty Liddiard](#), a disabled sociologist from Sheffield University in the U.K., recently interviewed a small number of disabled men who have paid for sex. Their reasons included gaining sexual skills and experience, invigorating the body, having something to chat to male friends about, and a sense of independence. Such reasons, she concludes, “take us far beyond the usual discourse of ‘men—especially disabled men—need sex,’” adding: “Quite often men would conflate sex with intimacy, hence dissatisfaction and being left with the feeling of wanting more.”

Although she believes that the legalization of sex work would make it a safer form of employment for women, she adds: “I think the focus on sex work is because we live in a patriarchal culture where men’s desires are more nurtured. My research shows that disabled men, growing up, had more space to speak about their sexuality than young disabled women, who reported that they couldn’t claim their sexuality.”

Alex Ghenis, an American disability advocate and former dating and relationships columnist, is unconvinced: “It commodifies sex in terms of an action. It makes it so society can check this box that men are getting laid, so we don’t have to have broader social change—we are giving them sex through a brothel, so we don’t have to change our social attitudes around socially excluded people with disabilities.”

“And it pities and coddles us, as if we are being given things that will assuage us ... rather than have society change around us,” Ghenis adds.

Mik Scarlet, a disabled TV presenter and musician influenced by punk and Goth culture, is currently an advice columnist at the disabled people’s organization

Enhance the U.K. It runs [Love Lounge](#), a website that offers advice on sex and relationships to disabled people. “Imagine this,” he says. “I’m disabled, growing up in Luton, and it’s now legal for me to go to a brothel—to have sex for money—because apparently that’s the only way I’m going to lose my virginity.”

“Instantly, my relationship with sex is distorted, and it means that everyone I meet afterwards is going to say, ‘He’s disabled, that means he’s paid for sex; I don’t want to go to bed with someone who’s paid for it.’ You’ve reinforced the fact that you can’t give it away because you’ve paid for it.”

---

**"It's now legal for me to go to a brothel, because apparently that's the only way I'm going to lose my virginity."**

---

“We are reinforcing the idea that some people are too hideous and too disabled to have sex like the rest of us, and so they have to pay for it. And why is it OK to oppress women, to make their bodies a commodity? It’s not all right just because we are on wheels. I want to live in a world where I am perceived as viable a sexual partner as anybody else.”

And he is concerned about consent issues around sex work for some disabled people, however benign the aim. “If someone is on a level of disability where they are not able to give consent, if they can’t say yes—and there are many ways of doing so—then that’s it.”

“You have to protect people. I’m afraid whether you like it or not, it is not their right to have sex. Lots of people who are not disabled do not have sex. It is not a right.”

\* \* \*

Most debates around sex and disabled people in the mainstream press mirror those of medical ethicists, by focusing on whether disabled people have the right to pay for sex. But this is just one small part of the overall picture.

Disabled academics and activists paint on a much larger canvas, writing about issues such as consent around mental capacity, the forced sterilization of disabled people, the rights of disabled people in institutions to have sex and be free from sexual abuse, and the rights of lesbian, gay, bisexual, and transgender (LGBT) disabled people.

Sexual politics has only recently become part of the disability rights agenda, says Liddiard, who has also carried out groundbreaking research in the field of disabled women's sexuality. She points out that disabled women experience far higher rates of sexual violence than non-disabled women and that there are very few services for disabled people seeking refuge from abusive relationships.

Ju Gosling is a disability-rights activist and the author of *Abnormal: How Britain became body dysphoric and the key to a cure*, a book that exposes the treatment of those with "abnormal" bodies. "Most women we know are looking for a relationship, and disabled people are no different," she says. She has concerns that women with learning difficulties are prevented by those around them from having sexual relationships because they are vulnerable to exploitation.

---

## **In some supported housing for people with learning difficulties, only heterosexual partners are permitted to stay overnight.**

---

She is also a campaigner for LGBT rights, and estimates that one-third of LGBT people have impairments. The barriers facing LGBT people with disabilities can be very different to those of LGBT people without disabilities, says Gosling—particularly when they depend on support from personal assistants or carers, some of whom will not approve of their sexuality and will even attempt to control it.

She gives the example of supported housing for people with learning difficulties where heterosexual partners are permitted to stay overnight, but gay or trans partners aren't. Later in life, people may move into care homes where their

sexuality is also frowned upon. “This is about someone’s right to be who they are,” she says. “People should not have to hide their love anymore.”

\* \* \*

Mik Scarlet thought, as many teenage boys would, that his sex life was over when his spine collapsed in his teens and he was no longer able to get an erection. Meeting lesbian friends soon after rescued him, he says. A few years later, he met Diane Wallace, and they’ve been together for over 20 years.

“I know that sex is so much more than penetration,” he says. “Lots of disabled people have sex like everybody else, but for some of us our sex is not like everybody else—but that doesn’t mean it’s less. You can make somewhere else your erogenous zone, for instance, if you don’t have sensation in your genitals anymore.”

“There is so much ignorance,” says Diane. “People assumed our sex life was over because Mik was disabled. But there was a raw sexuality about Mik; he was so easy and confident.”

In 2003 Penny Pepper published *Desires Unborn*, a groundbreaking book of short erotic stories featuring disabled people. “I do feel I can talk about sex in an open and relaxed way that I don’t see with many non-disabled people,” says Pepper. “I think it’s because we’ve had to confront these issues about body image and that’s a good place to be.”

She cites, for example, the fact that she was able to ask a former personal assistant to place her and her then-partner in a position for sexual intercourse: “It involved chairs, he was visually impaired, maybe it’s a comedy sketch!” But, she adds: “Sex has a central role as a pathway to pleasure. There is so much pressure on everybody who is outside the body-beautiful stereotype [whether they are disabled or not].”

At UC Berkeley, the Disabled Students’ Union is continuing to push boundaries and has hosted no-holds-barred panel discussions for students and academics, entitled ‘[Are Cripples Screwed?](#)’ They examine issues surrounding disability, love, and sexuality.

In a [documentary about the panels](#), one student who had been dating a non-disabled woman was particularly touched, he said, when “she suggested we had sex in my wheelchair. It was an ultimate act of acceptance.” A young disabled woman talked eloquently about sex being “anything that I can get off on. This brings us back into the human race.”

And that’s really the point. Disabled activists, patiently, are making some valid points about sexuality that hold true for everybody.

When Mik Scarlet says that penetration is not sex, he’s speaking for older people, too, or for women who don’t like penetration after sexual assault, or for men whose penises have been amputated or damaged after cancer or injury. The fact that some disabled people have developed erogenous zones in non-genital areas, such as the shoulders or inside the mouth, is knowledge of use to everyone who would like to extend their understanding of sexuality. Sexuality does not have to revolve around the genitals, or indeed around heterosexual norms of penetration.

Liddiard found this the most empowering part of her research. “Disability and impairment can invigorate sexuality, and disrupt our standard norms of gender and sexuality. Disabled bodies give us the chance to think outside of the box, outside the vision of penetration, the Hollywood view of sex.”

Disabled people, by defying some of the damaging myths around sex, may end up liberating all of us.

---

*This article appears courtesy of Mosaic.*

#### **ABOUT THE AUTHOR**

---

**KATHARINE QUARMBY** is a journalist based in London.

---



