

RESEARCH

The Sexual Politics of Disability, Twenty Years On

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This paper follows up on qualitative interviews conducted with British disabled people in 1994–6, exploring how people's lives and relationships have changed over twenty years (n = 8). The themes include imagery and identity, access to relationships, social context and attitudes. Ageing brought greater self-acceptance, and also lower salience of impairment; but for some, it also brought co-morbid chronic health issues which made life more complicated. Respondents generally felt that social attitudes to disabled sexuality had not changed sufficiently, but also that UK austerity policies risked undermining hard-won independence and wellbeing.

Keywords: Sexuality; Relationships; Identity; Self-image; Ageing; Austerity; Follow-up study

Introduction

The Sexual Politics of Disability (Shakespeare et al 1996) was pioneering for two things. First, it opened a space for disabled people to talk about their sexual lives. A group of 42 disabled people, mainly associated with the disability rights community, discussed their identities and self-image, talked about their experiences, and expressed their hopes and fears around sexuality and relationships. Second, the book placed disabled sexuality within the context of disabling barriers, rather than individual deficits. The authors summarized the book's message as 'the problem of disabled sexuality is not "how to do it" but "who to do it with"'. When they wrote the book 20 years ago, their assumption was that it would be the first of many similar studies.

Although research has continued over the last two decades, studies reporting on the lived experience of disability and sexuality continue to be thin on the ground. For this follow-up paper, the authors reviewed publications over the last twenty years in five relevant academic journals (*Scandinavian Journal of Disability Research*, *Disability and Society*, *Alter*, *Sexuality and Disability*, *Sexualities*). In the first edition of *Scandinavian Journal of Disability Research*, Gisela Helmius published important research about sexuality of women with congenital impairments (Helmius 1999), but with a few exceptions, sex and sexuality have not played a significant part in the journal content since then. Papers about sexuality and relationships pop up intermittently in *Disability and Society*, but often concentrating on the issues of sex work (Sanders 2007, Fritsch et al 2016) and sexual facilitation (Earle 2010, Bahner 2015), or else issues of sexual abuse – all of which are important, but perhaps not central to the everyday expression of sexuality for most disabled people. A very positive exception is the empirical research by Kirsty Liddiard (2013) on the emotional work which disabled people perform within relationships. The journal *Alter* has published very few papers discussing sex and sexuality (e.g. Giami and de Colomby 2008; Dupras 2012), but these papers do highlight the influence of the social context. The journal *Sexuality and Disability* still tends to be dominated by papers about sexual dysfunction. The extensive research about people with learning difficulties in the journal is largely focused on sex education, from the perspective of teacher or parent, and/or prevention of abuse. Although to the editors' credit, the journal *Sexualities* has had several special issues exploring sexuality and learning difficulties, and sexuality and pleasure, disability-focused papers remain otherwise rare in the journal.

The wider human rights context has developed since 1996. In 2008, the UN Convention on the Rights of Persons with Disabilities came into force, and because Article 23 (Home and Family) and Article 25 (Health) both reinforce rights in the areas of partnering, parenting and sex education, this has helped put sexual rights more firmly on the disability rights agenda. For example, in a key socio-legal article, Liz Emmens discusses how what she describes as the accidents of sex and love – who meets who, and who has access to the social, cultural and economic capital to be appealing – are nevertheless structured by access to employment and education and public spaces:

'...by deciding the form of our communities' institutional and physical infrastructure, the state has shaped who meets whom, who interacts with whom, who has the chance to fall for whom.' (Emmens 2011, 1380).

This clearly reiterates the message of the 1996 study.

Over the last twenty years, there has been extensive research and policy work with and about people with learning difficulties and sexuality. To take a few examples, Fitzgerald and Withers (2011) conducted research focused solely on the thoughts and feelings of women with learning difficulties with regard to their sexuality and sexual identity, highlighting how previous research has focused on sexuality in women with intellectual disabilities from a sex education or sexual abuse perspective. Similarly, Andrea Hollomotz (2011) reported on a study with 29 people with learning difficulties, in order to contest the notion of inherent vulnerability. She pointed to the role of over-protection in undermining the potential for competence:

'Undue protection from risks and opportunities associated with everyday life may disable individuals from becoming competent social and sexual actors and from accessing information and services that have the potential to reduce sexual "vulnerability".' (Hollomotz 2011, 1).

Many authors have pursued this important emphasis on consent and capacity in sexual relations for people with learning difficulties (e.g. Gill 2015, Arstein-Kerslake 2015).

Despite the provisions of the CRPD, people with learning difficulties are still not respected as sexual decision-makers, in the same way as others. In fact, 'legislation on capacity to consent to sex can be a barrier to intimate relationships for people with intellectual disabilities' (Arstein-Kerslake 2015, 1459). Indeed it could be argued that the conflation between mental and legal capacity has been used to deny people with learning difficulties the right to participate in sexual relationships by demanding their decisions are scrutinised to a greater degree than those without learning difficulties.

But more positive evidence about the sexual and social lives of people with learning difficulties comes through in a US study by George Turner and Betsy Crane (2016). Another project brought together people with learning difficulties in UK and Canada to debate what intimate citizenship might mean for people with learning difficulties in the era of Austerity (Ignagni et al 2016).

This focus on the context in which disabled people make sexual and romantic choices and lead their lives was the basis of a landmark book, Don Kulick and Jens Rydström's *Loneliness and Its Opposite* (2015). Their study focuses on the difference between attitudes to sexuality and disability, and practices, in Denmark – where people with significant disability are supported to express their sexuality – and Sweden, where a zero-tolerance policy on sex work has rendered disabled people excluded from assistance around sex. In a same vein, Julia Bahner's research in Sweden gives examples of how services for disabled people are obstacles to sexual encounters (e.g. Bahner 2012).

Turning from academic research to everyday life, we could ask the questions: have things changed for disabled people? Are disabled people still seen as asexual? Are there still barriers to sexual expression? Here there seems to be a distinction between what disabled people do, and what other people think they do. For example, Esmail et al (2010) report on a Canadian study which found that asexuality was still a key theme in discourse about disabled sexuality. Similarly, Liz Emmens suggests:

'normative desexualization is about utter exclusion of disabled people from the intimate realm.' (Emmens, 2009, 1338).

But the continuing emphasis on asexuality in discourses does not correspond to what seems to be going on. For example, Emmens herself highlights US data showing that around 50% of people with severe disabilities, 60% of people with non-severe disabilities and 68% of nondisabled people are married (Emmens 2009, 1326). In the research that Shakespeare's team conducted with people with restricted growth in Northern England, 47% of respondents were single, compared to 30% of the general population. 41% were married or in a long-term relationship, compared to 60% of the general population (Shakespeare et al 2009). Equally, evidence shows that disabled people are heterosexual, bisexual, lesbian and gay and transsexual, in much the same ways as nondisabled people (Abbott and Howarth 2005, Bedard et al 2010), as was also found in the 1996 study. In other words, a significant proportion – 50% or more – of disabled people are enjoying access to sex and relationships, which should dispel the asexual myth.

The Sexual Politics of Disability came out the year after the UK Disability Discrimination Act, and undoubtedly since then improvements in access to transport and venues has enabled more disabled people to participate in British society. Support for personal assistance has also helped people live independently in the community and access public spaces. As many disabled people get on with sex and love in much the same ways as the non-disabled population, attitudes are slowly shifting, perhaps more rapidly for people with physical and sensory impairments than for people with learning difficulties (Morales et al 2011).

Challenging the taboo around disability and sexuality remains relevant, twenty years on. Particularly for people with physical impairments, questions of body image relate to attitudes to disabled people as sexual beings and as equal citizens. More images of disabled sexuality – such as *The Sessions*, for example, or *The Undateables* (Channel 4) are now included in mainstream media, although these remain controversial among activists because they seem to ghettoize disability into a spectacle. Greater coverage of the 2012 and 2016 Paralympic Games shows fit, strong young disabled people, shattering some assumptions about physique and competence, although disability activists, including Paralympians themselves, are not wholly convinced of the positive difference this has made to the lives of less physically fit disabled people (Grue, 2015). An exploratory investigation into disabled activists views on the Paralympic games found that in practice, the sporting and political elements of disability appear not to meet at any level and to operate in isolation: 'Participants... revealed that the portrayal of equality in the Paralympics is an apparent misnomer when compared with the lives of ordinary disabled people' (Braye et al 2012, 994). Nevertheless, it may be that more positive images of athletes and other high achieving disabled people in the media might help change perceptions of disabled people, and their ideas of themselves.

Literature, legislation, policy and media therefore reveal a mixed picture, when it comes to disability and sexuality. This follow-up study asked the questions: what has changed for participants in the 1996 research? How does ageing intersect with disability and sexuality? Is the world more welcoming of the sexual lives of disabled people in 2016?

Methods

There were 42 participants in the 1996 book, which used a combination of methods – interviews, survey and submission of personal narratives. At least a quarter of the 42 original participants are known to have died. Using social networks, contact was made with eight of the remaining participants. Copies of the information sheet and consent form were circulated, and everyone agreed to be interviewed face to face or via the telephone for the follow-up study. Semi-structured interviews, lasting around 60 – 90 minutes were conducted with each participant by one of the two authors, based on an aide memoire which followed the structure of the 1996 book. Interviews were all transcribed. Thematic analysis was conducted separately by the two authors, coding the data for emerging themes and categories, and then comparing analyses. The 2015–16 study received ethics approval from the University of East Anglia Faculty of Medicine and Health Sciences research ethics committee.

The eight participants comprised two heterosexual men and two heterosexual women, two gay men and two lesbian women. Two participants were of Middle Eastern origin – one Arab, one Jewish. One participant had learning difficulties, one identified primarily as a survivor of a mental health condition, one had visual impairment, and the remaining five participants had physical impairments. They lived in the London region and in the North East of England. All but one were working. Names and identifying details have been changed.

Results

The themes of 'ageing and identity', 'sexual relationships', and 'wider social contexts' emerged as the most coherent structure within which to report this rich qualitative data.

Ageing and identity

Now in their fifties, people seemed to feel stronger in their identities. Julia said:

I feel emotionally much stronger. I haven't been using the mental health services for ten years now which is huge for me. I've weened myself off medication entirely, which was my own choice, on my own mission, on my own journey. I'm still as angry about certain things but I choose my battles more carefully, you know. I'm not going to get sectioned for beating up a police officer anymore, you know, what's the point?

Because they had lived with health conditions throughout their lives, people felt they were more able to deal with ageing. For example, Jenny said:

...I also think, ironically, whatever comes with age... it is that, we've got experience of managing that, for different reasons, so I certainly won't stop having sex, because I already know how to manage those things. Whereas it might be a shock to a non-disabled person, suddenly realising that their back is not as good as it was.

Disability was not as salient as it had been when they were younger, as Daniel indicated:

There's an equalising process in ageing, I feel less different probably, because everyone is getting older, and this hypothetical ideal that society says we are meant to live up to is less likely for anyone as we get older... because the premium is on youth. So in a way that equalising measure is reassuring, really. I'm more like everyone else, a creaky guy.

For Jasmine, a heterosexual woman, this meant that older men were more likely to accept her:

I get more offers now from older men, disabled or non-disabled, than I did when I was younger, when young men are all after their trophy bride, whereas older are not really looking for that, they are looking for companionship, friendship and so on.

However, the downside of ageing was greater co-morbidities and complications. For example, Eddy had had chronic health problems and an organ transplant:

When I have time to kind of step back and reassess things, yes I'm still proud of who I am, my identity and everything, it's changed you know, things have changed, my body has changed, I've got more scars now than what I used to. But that's fine, I don't have a problem with those at all. I find them very interesting, it changes my body.

Similarly Dafydd said:

It's like all of us as you get older as a disabled person you develop all these other medical conditions, comorbidity, so for instance I'm now diabetic so, you know, and I have a machine at night that I have to plug into, and stuff like that. I think the one thing I've struggled with is my hearing because I'm now profoundly deaf on this side, and you know, I love the chat, I love people around talking, so I do struggle with it.

He too thought this was a levelling effect with non-disabled people. Jenny had also had chronic health conditions – a heart problem and mental health issues. This connects to wider evidence highlighting how disabled people age earlier than non-disabled people.

Although older people, our respondents were still keen to portray their own identity. Jasmine's comment sums up what most of our respondents said:

I am getting older, but a number of people have said that I look better now than I did when I was younger... I look older now, but I feel far more empowered now, both in my looks and how I feel than I did then. Probably because I am more confident, and the way I kind of dress and take a lot more control....

Kristen also related changes to the way she chooses to dress and present herself:

I still dress smartly although I no longer wear skirts. I am still strong but not as 'full-on'. I have mellowed, life is too short, I am 60 next birthday. I pick my fights more carefully and you can't fight everyone's battle for them. I used to rant on and leave people with nowhere to go, but I leave them a little wriggle room now. I still get what I want but I am more silver-tongued!

Daniel's testimony echoed the way women and men sought to control their self-image:

I've always liked style, to a certain extent. You know, as I became more financially independent, with more disposable income, you can make those choices more easily... I think I feel confident in terms of the presence which I generate... And I feel much less anxious about appearing to be a disabled person, because I have a noticeable impairment, much less anxious about that than I used to....

For three of the men, self-image came through partly in their facial hair. Andy discussed how he'd emulated his hero Billy Connolly in his goatee. Eddy said:

I love playing with the image, whether it's kind of like you know having the handlebar moustache or having like cos what I've been doing is growing this part of my beard so it's really long, usually I don't have this, so it would just be the goatee, and then shaved head and it's very kind of biker look you know....

Dafydd said:

I feel like I've grown into my body more that whole bear culture, so I think I fit into that a bit better now 'cos I feel like I have a stronger gay identity in some ways because of bear culture, you know, I'm big and have a beard now, and you hang out with big bearded men, and have a hairy chest, and that's how I met my partner!

Jenny, a heterosexual woman, had also found acceptance in a sexual subculture, BDSM (Bondage – Domination – Sado-Masochism):

I know I can scrub up quite well, when I have my corset on, and all my make up, and you know I've got tits and so would attract people... I've got a disabled body, you know, an impaired body, I've got body difference, but somehow, ...it would attract men and women, and then... people would come to me quite easily... and that was quite liberating.

Andy's response to the question of identity was very much the same as he'd said twenty years before:

I'll just say, if people, like, just say someone with a disability, if you just see the person first and then the disability second.

Interestingly, several people mentioned that their own attitudes to another minority, transgender people, had changed since 1996:

Over the last 20 years I have changed in my attitude towards trans people, before I had similar attitude towards those who were bisexual – basically make your mind up who you are – now I am much more accepting and wish I had come to that point sooner. (Kristen)

I always have a certain fear of the unknown. [...] I've met so many more trans people and people who were born with intersex conditions, and that's only happened over the last 10 years...and it's changed my mind and my heart.... And the whys and the wherefores are not my business but I can see the journey matters deeply and that transition has brought each of them great peace. (Julia)

Sexual relationships

As in 1996, there were many positive reports about active sexual lives. For example, Jenny had shared a vivid sexual narrative in 1996, and twenty years later told us:

I've done burlesque, I've got my breasts out for the world... I got into kink. I wanted to try everything, alternative sexualities... There's something incredibly powerful with being submissive in that scene, people become scared, but actually it makes you, I feel really powerful, even if I'm a submissive, because I'm controlling my own....

She had felt very welcomed in the BDSM scene, reporting that her impairment was not a difficulty in this context, where everyone was diverse: this testimony supports the hope of Andrea Hollomotz (2013) that greater sexual openness might be empowering for disabled people.

Daniel, a gay man, had been tentative about sex in 1996, but now reported:

I do have more sex...than I used to... I used to be much more terrified of sex, and I am certainly much less terrified, and I do have sex.

But he also said:

I've continued to struggle with having a long term permanent partner. I understand more and more however that this is largely to do with how I feel about myself and about relationships, rather than how other people feel about me... I used to think my relationship difficulties were because I was disabled, but I actually think that that's much less true than I had ever give credence for...

He had intermittently paid for sex and used escorts:

There was a time when I was paying for sex. But I found that deeply uninteresting. Because I realise I have no interest in having sex with somebody that I didn't have an emotional connection with. [...] There was one guy I had sex with that I really liked, mainly because he was so enthusiastic, he made me laugh. I think it was a solution in some respects, this is very much to do with me and I think it's a bit different for everybody... it was a way in which I could take some control over a situation.

Dafydd, who also discussed sex work, was more critical:

I think that's just a poor substitute for spending the time and effort to help somebody support somebody in getting the sex that they want... I'm not saying people shouldn't be physically assisted to do that, but I just don't think prostitution is the assistance.

The internet, transformative since 1996, was another channel for meeting sexual and romantic partners, and had the advantage of being barrier-free, as Jenny reported:

I think that the internet is a mixed blessing, actually. I think it's been extremely liberating. I've done chat rooms, sex chat rooms. And sometimes for a laugh. Really, if you can write, you rule those places. You can end up with loads and loads and loads of genuinely strange people, because I immediately excite them... But you have to be quite mature to chat.

Dafydd talked along similar lines:

The gay community, like the clubbing, the young people, I can never fit into that now anyway so and that's not just to do with being disabled it's age now... but I think Facebook and the Internet have been really good for that [...] so I can have conversations with other gay men, and stuff and keep up-to-date with stuff and participate in dialogue you know without that barrier, that's quite interesting so that's quite useful. There's things like Growler Grindr you know and that's just very immediate and very accessible again so you can flirt with a lot of men very quickly. You are being judged but then even somebody who looks great is being judged so I think for me as a disabled person it doesn't it didn't feel any different when I did that.

For Andy, as a man with learning difficulties, education was key to being empowered to have a positive sexual life:

I think people with disabilities should be made aware of sex education as well as all of it how to be safe if you do go into a relationship and you don't want to get pregnant this is what you've got to do or this is what you've got to do or this is what he's got to do or she's got to do to safeguard yourself from anything.

Interestingly, he conceptualises safeguarding as something a person does for themselves.

Jenny, Dafydd and Eddy were all in long-term relationships. Jenny's partner also had chronic health issues, while Dafydd and Eddy had non-disabled partners. For Eddy, who had been married for nearly 20 years, his health issues had sometimes caused tensions and emotional difficulties for him and in his relationship:

I think just a lot of the stuff that's happened to me as well, spending lots of time in the hospital, having loads of procedures and stuff, you have to kind of like reassess... I think that for me that has been a difficult thing, because the woman I married has at times taken on a role of almost like a carer, I mean I'm still very independent... there are times when she will try and help and I will get pretty angry, and I mean, you know, there sometimes there has been anger towards myself, when I'm kind of, self-harmed.

Conversely, Dafydd had avoided questions of dependency because he always had a personal assistant, but this might also generate other difficulties around privacy:

I think I'm very lucky and it goes back to me having full time assistants and that my lover doesn't have to do that, but there's still a trade-off and that's like, how do I arrange our privacy if I've got somebody within earshot you know, or sight shot of me all the time, so negotiating that has been a big thing for me and it's different with each person.

Julia reported having had many relationships – “in the last five years, I've been somebody's daddy, somebody's helpmate, somebody's miracle worker...” but said that now:

I've become a crossy old bachelor and I think I would just...I quite like being on my own. You know I can't...not having to be having to be held to everyone and accountable to anyone. I can do what the hell I like. The love of my life is my mum's dog.

However, several of our respondents were not in relationships or accessing sex. For example, Jasmine, a committed Christian, reported that she was celibate:

I find most men irritating. [laughter] They're demanding... And I think a lot, it all stems really from my own independence, and because, you know, not wanting to make excuses, I've had a children's home upbringing, you know, where you fought your own corner all the time, you become very independent, I've become very independent. I love having friendship relationships with men, but don't want them in my house really.

Kristen, a lesbian, said:

I don't need the validation of one other person or seek all needs from one other individual. I have a network of female friends, we all support each other....

However, she knew people in polyamorous relationships and had considered this for herself. Andy, who had learning difficulties, had had several relationships over the years. One had floundered on the fact that while he lived in the North East, his partner lived in London, and neither of them had support to move. Since then, he said:

There's been one lass I saw, but it was just getting too much hassle so that's by the way now, but otherwise I'm just happy the way I am.

Overall, while half this sample were sexually active, our data does suggest that it may still be harder for disabled people to start and maintain long-term relationships than it is for non-disabled people.

Wider social contexts

Although, twenty years on, our respondents were more secure in themselves, they felt that the status of disabled people in wider society was still problematic. Access barriers were reduced, as Jenny noted:

If we look across the impairment spectrum, where you can pretty much find somewhere to go for a date which is accessible and has a toilet, that's improved massively. Not as many as you might like, but you can, you will be able to find somewhere. Particularly in London and most major cities you have accessible buses now.

But social attitudes were still negative, as Julia for example reported:

So once people discover you've got a brain injury and a mental health condition, they go into all sorts of weird spaces about what might happen and fear and well what does that mean then? What do you do? What are you going to do to me? I mean, I had one partner who said "actually I think it's best we sleep apart and you know what sometimes I might need to lock the door" and I go "what's going to happen? And if you lock the door, is that to feel safe and therefore I now feel really unsafe, what's out there? I just don't know what you're going to do", and I found that really unhealthy, so I had to get out of that.

Jenny also felt that social attitudes had not changed much:

I don't think we're more accepted... A little... I think the asexual thing is less. But I still think it's surprisingly taboo... and also I think generally we've had that polarisation, not just for disabled people because we've got the whole Paralympic thing... there's now Scroungers, Strivers, Paralympians, and those of us who they don't know what boxes to put in.

Jasmine thought there had been little change in attitudes towards disabled sexuality since 1996:

I still think it's taboo. It depends on who you talk about or where you are. In my spheres, the only time we really talk about sex is when I am talking around other disabled people, and then it's not taboo, you know.

Others felt that the prevailing social attitude was that it was okay to be disabled as long as you are beautiful and symmetrical. Julia said:

...generally, we've had, no favours done us from the media, absolutely no favours from some of the... what I call disability porn on television.... where actually it's still a freak show... *Castaways*, *Embarrassing Bodies*... But yeah, disability porn, roll out the freaks, let's all stare and glare and there's still some of that "there but for the grace of God". *The Undateables* – you know. I hate the title, I hate the framework. I mean just the way it presents people...

This negative feeling about Channel 4's *The Undateables* was shared by all respondents who mentioned the programme, for example Jenny compared it to a wildlife documentary.

Interviewed in 2015–16, the big issue on most people's minds were the cuts to welfare benefits and independent living. Dafydd and Jenny both relied on 24/7 personal assistance to live independently in the community.

Dafydd echoed several other respondents in talking about the availability of support:

Social services it's gone backwards, so how can you possibly have a sex life if you can't even be clean and washed and feel sexy? So I think these cuts are having a direct effect on our sex lives. It's pie in the sky now, when you're somebody coming to your house for three one hour visits a day, food in, food out and that's it. It's not going to be "Do you want support to go out flirt with someone?", it's going to be "We'll give you support if you need to have an injection cos you can't do it yourself", and I've had that discussion already... if you're fighting just to get

your arsed wiped how do you even begin that dialogue with social services to talk about positioning for sex then, are they going to see that as frivolous?

He felt that while in the years after 1996, the position of disabled people in the community had improved, the situation had worsened with the onset of austerity after the global financial crisis of 2008 and the Coalition/Conservative governments since then.

Jenny also identified a direct link between the effects of austerity and the sex lives of disabled people:

Sex is kind of an ultimate experience or whatever... but even now we need to ensure that people can have support to get it. [...] So the people who are classed as most severely disabled are now facing this huge challenge... there are very little areas to go with it now, except to challenging at local authority level. And you've got to start with that. If you can't guarantee you're going to get up, be washed and fed, where on earth can you hope to look for a relationship?

Kristen, a party political activist, said:

Austerity is disproportionately affecting people with disabilities, cuts to benefits and the ILF, people can't work or even go out. Austerity has become so fashionable, it's pornographic! It's now worse than the Thatcher cuts in the 90's. At the same time there's two Bills on Assisted Dying – at a time when people don't have enough to live on they now want to make it easier for us to die.

Yet looking to the future, people still felt positive about themselves as disabled people. Daniel, who was probably the most economically secure respondent, working in an executive role, said:

I have more worries about the world than I do have about my own situation. I want to do more of what I like, which is closeness and connection, ideally to live with someone, although that has its challenges. I love work, I enjoy work, so hopefully I will carry on working.

Even Dafydd, who was no longer working, said:

Despite all of this I'm still optimistic I'm quite happy at the moment [...] Interestingly the one thing that's a danger to that is losing my assistance, funnily enough it's like I'm even thinking about having a child, you know, I really am [...] Thinking about the future, so all of a sudden I feel like there's possibilities laid out before me, but they are dependent on me still having enough assistance to have choice and control. If I don't, then I become done unto, and that feels quite abusive, like a passion killer....

Discussion

A small study like this cannot represent the diversity of disabled experiences in the UK. However, the eight life history interviews collected for this follow-up study represent a rare example of longitudinal qualitative research. They speak to the importance of what Ken Plummer calls “intimate citizenship”, something which should run alongside civil, political and social rights (Ignagni et al 2016):

The control (or not) over one's body, feelings, relationships; access (or not) to representations, relationships, public spaces etc.; and socially grounded choices (or not) about identities, gender experiences, erotic experiences. (Plummer 1995, 151).

Much literature on disability and sexuality focuses on contentious and/or negative issues – abuse, consent and capacity, sex work – whereas this study also contributes to our understanding of more positive aspects of lived experience.

Looking at these eight individuals, this evidence highlights the need to understand issues that arise when people are ageing with an existing impairment. On the negative side, disabled people potentially experience greater health complications, but may also benefit from a less stigmatising attitude to increased physical needs in later life. As with many people, non-disabled as well as disabled, ageing brings greater confidence and self-acceptance. The need to understand sexuality as a dynamic and changing aspect of life – including later life – is reinforced by this study.

Wider societal changes include the positive – internet dating and better access (Löfgren-Mårtenson 2008) – and the negative – austerity and worsening social support (Roulstone 2015). In particular, greater openness towards sexuality diversity and sexual expression may open up more choices for disabled people – as the testimony of Jenny highlights (Hollomotz, 2013). Other studies have explored heterosexual men's use of sex work (Liddiard, 2014): testimony in this study also highlights tensions amongst gay men, and similarly reinforces the need to explore power and agency around intimacy and sexuality. This evidence also highlights again the important role of personal assistants in enabling people

to enjoy their sexuality: the role of support workers in facilitation of sex has been widely discussed (Bahner 2015, Earle 2010, Gallo-Silver et al 2016, Kulick and Rydström 2015).

Despite challenges, all respondents were broadly positive about the future. It should be noted that the participants in the original study and the follow up study were people who had been associated in some way with disabled people's political or cultural activities, so they were not typical of the majority of disabled people. So this research has something to say about disability politics and identity as well. Although in 1996, most of the participants had been associated with disability rights groups, few of them were now active in disability organisations and they said they regretted that. For example, Daniel felt it was important for his self-esteem to spend time with other disabled people:

There remains a key role for us to think about and get alliances with each other, and have relationships with each other, for our internal benefit as well as more broadly. There's a political imperative because of the cuts in public services which are disproportionately affecting disabled people, but there's also an internal imperative, because although we have anti-discrimination laws and although there has been a dramatic change, it's doesn't mean that there's no oppression, and we still need to... I suppose, nourish each other really, and be positive role models for each other, and notice through our connections with each other that because we feel good about each other, we can feel good about ourselves.

One positive dimension is that Daniel, Jasmine and Kristen had moved on to work in mainstream political or non-governmental organisations, using the skills they had grown in the disability context for wider struggles. To ensure the continuing contribution of the disability rights movement, Penny placed her hopes in the younger generation of disabled people:

But I do worry, we still want them to be political enough to maintain that, to not let it slip away. I know there are younger people out there who are fighting tooth and nail. I don't think it particularly matters if they're in a group, as long as they know they are supported by others who've done that in a different way before them.

We might equally well express the hope that a new generation of social researchers will explore issues of disabled people's intimacy and sexuality, continuing to document and analyse the extent to which everyone is able to attain the sexual citizenship and sexual rights to which they are legally and morally entitled.

Competing Interests

The authors have no competing interests to declare.

References

- Abbott, David, and Joyce Howarth. 2005. *Secret Loves, Hidden lives? Exploring issues for people with learning difficulties who are gay, lesbian or bisexual*. Bristol: Policy Press.
- Arstein-Kerslake, Anna. 2015. "Understanding sex: the right to legal capacity to consent to sex." *Disability and Society* 30(10): 1459–1473. DOI: <https://doi.org/10.1080/09687599.2015.1116059>
- Bahner, Julia. 2012. "Legal rights or simply wishes? The struggle for sexual recognition of people with physical disabilities using personal assistance in Sweden." *Sexuality and Disability* 30(3): 337–356. DOI: <https://doi.org/10.1007/s11195-012-9268-2>
- Bahner, Julia. 2015. "Sexual professionalism: for whom? The case of sexual facilitation in Swedish personal assistance services." *Disability and Society* 30(4): 788–801. DOI: <https://doi.org/10.1080/09687599.2015.1021761>
- Bedard, Cheryl, Hui Lan Zhang, and Kenneth J. Zucker. 2010. "Gender identity and sexual orientation in people with developmental disabilities." *Sexuality and Disability* 28: 165–175. DOI: <https://doi.org/10.1007/s11195-010-9155-7>
- Braye, Stuart, Kevin Dixon, and Tom, Gibbons. 2012. "'A mockery of equality'. An exploratory investigation into disabled activists' views of the Paralympic Games." *Disability and Society* 28(7): 984–996. DOI: <https://doi.org/10.1080/09687599.2012.748648>
- Dupras, André. 2012. "Handicap et sexualité: quelles solutions à la misère sexuelle?" *Alter* 6(1): 13–23. DOI: <https://doi.org/10.1016/j.alter.2011.11.003>
- Earle, Sarah. 1999. "Facilitated sex and the concept of sexual need: disabled students and their personal assistants." *Disability and Society* 14(3): 309–323. DOI: <https://doi.org/10.1080/09687599926163>
- Emmens, Elizabeth F. 2009. "Intimate discrimination: the state's role in the accidents of sex and love." *Harvard Law Review* 122: 1307–1402. DOI: <https://doi.org/10.2139/ssrn.1694174>
- Esmail, Shaniff, Kim Darry, Ashlea Walter, and Heidi Knupp. 2010. "Attitudes and perceptions towards disability and sexuality." *Disability and Rehabilitation* 32(14): 1148–1155. DOI: <https://doi.org/10.3109/09638280903419277>
- Fitzgerald, Christina, and Paul Withers. 2013. "'I don't know what a proper woman means': what women with intellectual disabilities think about sex, sexuality and themselves." *British Journal of Learning Disabilities* 41(1): 5–12. DOI: <https://doi.org/10.1111/j.1468-3156.2011.00715.x>

- Fritsch, Kelly, Robert Heynen, Amy N. Ross, and Emily van der Meulen. 2016. "Disability and sex work: developing affinities through decriminalization." *Disability and Society* 31(1): 84–99. DOI: <https://doi.org/10.1080/09687599.2016.1139488>
- Gallo-Silver, Les, David Bimbi, and Michael Rembis. 2016. "Reclaiming the sexual rights of LGBTQ people with attendant care dependent mobility impairments." In: Michael Rembis, ed., *Disabling Domesticity*. New York: Palgrave Macmillan.
- Giami, Alain, and Patrick de Colomby. 2008. "Relations socio-sexuelles des personnes handicapées vivant en institution ou en ménage: une analyse secondaire de l'enquête "Handicaps, incapacités, dépendance" (HID)." *Alter* 2(2): 109–132. DOI: <https://doi.org/10.1016/j.alter.2008.02.002>
- Gill, Michael C. 2015. *Already Doing It: intellectual disability and sexual agency*. Minneapolis: University of Minnesota Press. DOI: <https://doi.org/10.5749/minnesota/9780816682973.001.0001>
- Grue, Jan. 2015. "The problem of the supercrip: representation and misrepresentation of disability." In: *Disability Research Today*, ed. T. Shakespeare, 204–218. London: Routledge.
- Helmus, Gisela. 1999. "Disability, sexuality and sociosexual relationships in women's everyday life." *Scandinavian Journal of Disability Research* 1(1): 50–63. DOI: <https://doi.org/10.1080/15017419909510737>
- Hollomotz, Andrea. 2011. *Learning Difficulties and Sexual Vulnerability: a social approach*. London: Jessica Kingsley.
- Hollomotz, Andrea. 2013. "Exploiting the Fifty Shades of Grey craze for the disability and sexual rights agenda." *Disability and Society* 28(3): 418–422. DOI: <https://doi.org/10.1080/09687599.2013.776816>
- Ignagni, Eesther, Ann F. Schormans, Kirsty Liddiard, and Katherine Runswick-Cole. 2016. "'Some people are not allowed to love': intimate citizenship in the lives of people labelled with intellectual disabilities." *Disability and Society* 31(1): 131–135. DOI: <https://doi.org/10.1080/09687599.2015.1136148>
- Kulick, Don, Jens Rydström. 2015. *Loneliness and its Opposite: sex, disability and the ethics of engagement*. Durham NC: Duke University Press.
- Liddiard, Kirsty. 2013. "The work of disabled identities in intimate relationships." *Disability and Society* 29(1): 115–128. DOI: <https://doi.org/10.1080/09687599.2013.776486>
- Liddiard, Kirsty. 2014. "'I never felt like she was doing it for the money': disabled men's intimate (gendered) realities of purchasing sexual pleasure and intimacy." *Sexualities* 17(7): 837–855. DOI: <https://doi.org/10.1177/1363460714531272>
- Löfgren-Mårtenson, Lotta. 2008. "Love in cyberspace: Swedish young people with disabilities and the internet." *Scandinavian Journal of Disability Research* 10(2): 125–138 DOI: <https://doi.org/10.1080/15017410701758005>
- Roulstone, Alan. 2015. "Personal Independence Payments, welfare reform and the shrinking disability category." *Disability and Society* 30(5): 673–688. DOI: <https://doi.org/10.1080/09687599.2015.1021759>
- Sanders, Teela. 2007. "The politics of sexual citizenship: commercial sex and disability." *Disability and Society* 22(5): 439–455. DOI: <https://doi.org/10.1080/09687590701427479>
- Shakespeare, Tom, Kath Gillespie-Sells, and Dominic Davies. 1996. *The Sexual Politics of Disability: untold desires*. London: Cassell.
- Shakespeare, Tom, Sue Thompson, and Michael J. Wright. 2009. "No laughing matter: medical and social factors in restricted growth." *Scandinavian Journal of Disability Research* 12(1): 19–31. DOI: <https://doi.org/10.1080/15017410902909118>
- Turner, George W., and Betsy, Crane. 2016. "Pleasure is paramount: adults with intellectual disabilities discuss sensuality and intimacy." *Sexualities* 19, nos. 5(6): 677–697. DOI: <https://doi.org/10.1177/1363460715620573>

How to cite this article: Shakespeare, Tom and Sarah Richardson. (2018). The Sexual Politics of Disability, Twenty Years On. *Scandinavian Journal of Disability Research*, 20(1): 1–10. DOI: <https://doi.org/10.16993/sjdr.25>

Submitted: 06 May 2017 **Accepted:** 10 May 2017 **Published:** XX Month 20XX

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