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Reproductive Rights: What Do They Mean for Disabled Women?

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On 27 June, 2017, the British Pregnancy Advisory Service (bpas) and the Royal College of Obstetricians and Gynaecologists (RCOG) hosted a workshop on the intersection of disability and reproductive rights, centring disabled women and their experiences in discussions of sexual and reproductive health. A group of distinguished individuals in the disability space from diverse backgrounds including academics, activists, and artists spoke about relevant issues and their personal experiences.

Claire de Than -- “Exploring the human right to have fun”

*Law Commissioner, Centre for Law, Justice and Journalism, City, University of London
Chair, Sexual Health and Disability Alliance*

Professor Claire de Than opened the conference with her presentation centred on “the human right to have fun.” Within this, she emphasised the need to balance the law’s desire or perceived duty to safeguard against risk with an individual’s human right to sexual expression. As she noted, all leisure and sexual activity necessarily involves risk—the fact of that risk alone is not enough to warrant permissible restriction on that activity for any person, disabled or otherwise. Risk acts as a limiter on a right, and cannot be allowed to proscribe that right entirely. Neither risk nor lack of capacity can negate a right. Historically, disabled women have often had their right to have fun circumscribed, often through indirect and underhanded means. Professor de Than gave the moving example of the case of MM, in which a young disabled woman was placed under 24 hour surveillance in order to inhibit interaction, and therefore prevent her having sex. The pretence of surveillance as a safeguard against risk has often been used to justify the limiting of a right.

Professor de Than centred her argument within a legal framework, noting that the human right in question has been explicitly articulated by the European Court on Human Rights as within the right to privacy. The Articles of the European Convention on Human Rights most useful in defending these sexual rights are Article 8 (private life) and Articles 9-11 (rights to expression). An array of ECHR cases has built up this right, including *Pretty v. UK*, *ADT v. UK*, *X v. UK*, and *Handyside v. UK*. Under this case law, any restrictions on this right must have very compelling reasons. This right as enumerated by the Court additionally includes the right to education and information—a component often especially neglected for disabled people, who simply may not receive sex education. Far too often, pernicious assumptions are made and disabled women are entirely discounted as sexual people, which impinges upon their exercise of a fundamental human right. Though the case law has created some protections, the law is overall far too complex. The reform agenda is to simplify these regulations.

Dr Jane Dickson

*Consultant in Sexual and Reproductive Healthcare and Community Gynaecology
Vice President of the Faculty of Sexual and Reproductive Health*

Dr Jane Dickson next presented a thorough review of all available contraceptive options, with a focus on highlighting disabled women’s difficulties in accessing contraception and pre-conception care.

As she noted, disabled women are often neglected when it comes to contraceptive care and consultation, owing to assumptions about their lives. The contraceptive methods she discussed included: combined pills, the patch, the ring, progestogen-only pills, Depo Provera (the contraceptive injection), the implant, IUDs, IUSs, emergency contraception, and the diaphragm. There are myriad issues which may affect or influence a woman's contraceptive choice, including weight, mobility, difficulty swallowing, desired outcome, and other medical conditions. Disabled women face unique difficulties in accessing and utilising contraception, which often make certain contraceptive options more feasible. For example, women who use wheelchairs are often at risk for blood clots—a risk that increases with use of the pill, making that a potentially less advisable option. The self-administered contraceptive injection is a good option for women with limited mobility, owing to its convenience and ability to be injected elsewhere besides not-easily-reachable large muscles. Dr Dickson highlighted the importance for doctors to consider the unique circumstances of disabled women's lives such as these when discussing contraceptive options.

Moreover, it is crucial that doctors utilise accessible facilities. A disabled woman may not be able to get on to an examination table, for example, and it is up to doctors to have other more accessible equipment so that all women can receive necessary healthcare. Lack of access also contributes to lack of representation—disabled women are underrepresented in smear test statistics. Dr Dickson raised the crucial question: whose responsibility is it to ensure that disabled women may access this care?

Alison Lapper

Artist, television presenter and speaker

Alison Lapper next spoke about her personal experience during her pregnancy, and later raising her young son. She faced huge obstacles and difficulties owing to her disability and in particular the attitudes of other people, from doctors and family to strangers on the street, who repeatedly questioned her fitness to bear and raise a child. A non-disabled woman would rarely be subject to such questioning. Alison said that she had been wrongly accused of neglect by social services on two occasions: once because she fell during a home visit, and another time because she was accused of sexually abusing her son by one of her assistants. Alison argued that disabled mothers are often viewed as inherently unfit by the social care system. The moving account of her pregnancy and motherhood is an illustration of the appalling way disabled mothers are often treated. As Alison experienced, the reproductive and sexual lives of disabled women are often disregarded or labelled as 'less-than'.

Dr Frances Ryan

Guardian journalist and political commentator

Dr Frances Ryan spoke of the way in which conversations around reproductive rights almost always shut out certain aspects of disabled women's experiences, if not exclude them altogether. Large topics in the arena of reproductive rights often become ignored completely when in the context of disabled women. Disability is only mentioned in the context of fetal anomaly—reproduction and disability begins and ends with abortion. Disabled women often face enormous difficulties accessing education about appropriate and accessible contraception that addresses their unique circumstances.

There also is a serious deficit in necessary sex education for disabled children for whom the topic may be neglected entirely. Moreover, disabled women may miss essential healthcare simply because a

doctor does not have accessible equipment. Other times, doctors may simply not do a sexual health check up, making an ignorant assumption at the expense of women's basic healthcare.

Dr Ryan also highlighted the way in which the cutting of social care packages often has the effect of limiting disabled women's reproductive choices. Several different sources of financial assistance for disabled mothers have been cut in recent years: historically, disabled women have always been more likely to be in poverty than their non-disabled peers, but this disparity has increased in recent years. Dr Ryan also spoke about the judgment disabled mothers often face. Disabled women are frequently viewed as a financial burden on the state and the decision to have a disabled child is either viewed as tragic or the mother is vilified as selfish. Overall, Dr. Ryan emphasized the vital need for a cultural shift away from seeing disabled women as sexless. Rather, we need to think of disabled persons as prospective parents and therefore respect their reproductive choices and decisions.

Panel Discussion (Q&A)

The four individual presentations were followed by a question and answer panel discussion. Each of the four presenters sat on the panel as well as Dr Melanie Davies, consultant obstetrician and gynaecologist at University London College Hospitals, and Eleanor Lisney, Founder Member and Coordinator at Sisters of Frida

Asked to introduce herself, Eleanor Lisney spoke to the difficulties that come at the intersection of being a disabled woman and a woman of colour. The obstacles to access she has faced as a result of the marginalisation of one of her identities have often been exacerbated by the other.

Following introductions, Ann Furedi, Chief Executive of bpas, asked the first question of the panel. Ann spoke about a conference in the United States, in which scholars had highlighted the damaging associations that come with the language of "choice" for disabled women. Speaking of "choice" in the manner common to reproductive rights specifically in the context of disabled women connotes an *expectation* that disabled women will need to access abortion. Ann asked the panel whether they were aware of or felt that similar issues were pervasive in the UK. Dr Frances Ryan responded to Ann's comments, noting that fortunately the deleterious controversy of this rhetoric is less of an issue in the UK. In the UK, there is a greater recognition that a disabled woman may indeed become a disabled mother. Eleanor Lisney agreed with Dr Ryan, but additionally noted that in the UK there is a harmful conception that because you are disabled, you are therefore ill-equipped to deal with another disability. This comes up especially in the case of testing for fetal anomaly.

Another attendee of the conference spoke about being on the autism spectrum and the way in which for some ASD women, having children may exacerbate disability in the sense that a condition such as sensory overload may heighten. She asked the panel about their knowledge of experiences such as the one she described. Dr Frances Ryan responded and emphasised the need to increase awareness about the varied birth experiences of disabled women, including those of women who are susceptible to sensory overload and similar conditions. Women's disabilities may deeply impact the quality of their birth experience itself, and scholars as well as medical professionals need to be more attuned to that.

Professor Claire de Than contributed to the discussion, noting the need to re-evaluate disability equality documents. Often, many of the assumptions in such documents need to be critically assessed and challenged. They are written for people with disabilities by people without them, and so need to be constantly challenged in light of that fact. Eleanor Lisney agreed with Professor de Than and additionally noted, in response to the attendee's comments about ASD women, that when thinking about disabled women in the reproductive rights space there is frequently too much focus on physical disabilities in particular, at the expense of recognizing the experiences of women with other types of disabilities as well.

Following this exchange, another conference attendee spoke about her experience being denied sex education and highlighted the crucial need for such education for disabled individuals. It's critical that this whole realm of education not simply be ignored for disabled persons owing to offensive assumptions about their sexual and reproductive capacities and desires. Professor Claire de Than responded, agreeing with the attendee. Professor de Than emphasized the need to accept that people with disabilities are allowed to take risks. It is a normal developmental stage and not one that should be denied disabled women, nor problematised for that population. Professor de Than also highlighted the need to standardise and improve capacity assessments. As an example of one issue with its current form, she noted that the present capacity assessments often centre on very invasive lines of questioning that are only ever used on those individuals with disabilities.

Closing Comments

The meeting was closed by Professor Lesley Regan, President of the RCOG, who highlighted the need for a cultural shift in how society views disabled women—so that they are not discounted as sexless and are instead accorded the proper dignity and care that they deserve. It is imperative, she emphasised, that we as a society focus on what women want, as opposed to what doctors and midwives want, or what may be easier for them.

Further Reading

[Talking about Sex, Sexuality and Relationships: Guidance and Standards for Those Working with Young People with Life-Limiting or Life-Threatening Conditions](#)