

Contraceptive Choices

A team from the Open University discuss their research into contraception

Contraception for women with learning disabilities is a little discussed topic. It's something that has interested us at the Open University for some time, as it is both a hidden health issue, and reflects important attitudes about women in general and about learning disabled women in particular. Here we report on our latest research, when we interviewed nineteen women about their experiences of choosing contraception – or not. This followed an online survey in which we asked the views of third parties including family members, advocates and health and social care practitioners¹.

The question of contraception is overshadowed by a eugenic history, with many countries legislating for the compulsory sterilization of women with learning disabilities. While the law has changed, 'newgenetic'² social practices continue to restrict the sexual and reproductive freedoms of learning disabled women.

The UN Convention³ to which UK is a signatory states that people with learning disabilities have the same right to a family life as anyone. But anxieties about sex, relationships and parenthood remain⁴. Now that incarceration and sterilization are no longer acceptable, contraception and childcare proceedings have become the modern equivalent.

What is known?

The little research in this area highlights that:

¹ Earle, S., Tilley, E. and Walmsley, J. (2012) Who makes crucial decisions on reproduction and contraception? *Learning Disability Practice*, 15: 8, 34-35

² Tilley, E., Walmsley, J., Earle, S. and Atkinson, D. (2012) 'The Silence is Roaring': Sterilization, reproductive rights and women with intellectual disabilities. *Disability and Society*, 27: 3, 413-426.

³ UN Convention on the Rights of Persons with Disabilities 2006
www.un.org/disabilities/convention/conventionfull.shtml

⁴ Chapman R, Ledger S, Townson L with Docherty D (eds) (2015) *Sexuality and Relationships in the Lives of People with Intellectual Disabilities* London: Jessica Kingsley

Women frequently take contraception 'just in case', regardless of whether they are in or likely to be in a heterosexual relationship⁵

Decisions about contraception are frequently taken by others, mainly parents, carers and professionals⁶.

People lack sex education and knowledge of the law pertinent to their sexual rights. According to a recent study only 20 out of 60 people knew they had a right to marry; only 50 per cent realised that the law relating to sexual assault and rape applied to them⁷.

Doing the research

Our research was funded by the Open Society Foundations, explicitly to gain the perspectives of women with learning disabilities, including those with high support needs, about choosing contraception.

We included women who:

Have been users of specialist services for people with a learning disability

Could consent to take part without undertaking a formal assessment of capacity

Were using, intending to use, or had used contraception.

Working within an inclusive team of female researchers, we developed accessible information and consent forms, and an accessible questionnaire. We largely relied on gatekeepers to access women to interview. Given the sensitivity of the topic, this proved problematic. Without the enthusiastic

⁵ McCarthy, M. (2010a) Exercising choice and control- women with learning disabilities and contraception. *British Journal of Learning Disabilities*, 38, 293-302.

⁶Fitzgerald, C. and Withers, P. (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,

⁷ O'Callaghan, A. and Murphy, G. (2007) Sexual Relationships in Adults with Intellectual Disabilities': Understanding the Law. *Journal of Intellectual Disability Research*, 51: 3, 197-206.

support of two organisations whose managers recognized this was an important issue, the research could not have happened.

Our approach was flexible. We adjusted the method according to women's preferences and circumstances. Most interviews were one to one; some had support workers or advocates present; one woman was interviewed on Skype and some women participated in a focus group discussion. We tried to carry out the interviews in such a way that women felt comfortable talking about a subject that is often considered private and taboo, paying particular attention to the way that we asked questions and the location and layout of the venue for the interview.

What we found out

Talking about contraception with women with learning difficulties was sometimes challenging because there was not always a shared understanding of what contraception is, what it means and why and how it can be used. Our research findings present a mixed picture.

Some women had enjoyed sensitive support and felt well informed enough to make choices about contraception. Xanthe⁸ was one of these:

I don't take contraception unless I'm in a relationship. I don't see the point.

Only three women recalled sex education at school. All commented on its value.

More women, however, were poorly informed about their options. Shirley, for example

Interviewer: Why did you choose the implant?

Shirley: Doctor thought it was best in case I forget to take the pill

Several women were taking contraception to alleviate menstrual pain. However, there was no consistency in checking that the treatment was effective. Said Andrea (25)

Never had a period since I had the implant. Only a wee drop now and again. But I still get bad cramps, stops blood, doesn't stop the cramps.

Whether women made the decision to use contraception, or were persuaded to do so was often unclear.

Said Harriet (35)

Parents say don't have the wains. Dad says to me don't step back, step forward. Tablet. No wains.

Andrea indicated that seeing what happened to other women persuaded her to use contraception:

I never want children, would be too hard for me and social worker would take them away

Yvonne's experience, some years previously, was less ambiguous:

They forced me to have an implant when I was in the care home. They said if I don't have the implant they'd throw me out. I'll never forget that.

⁸ All names have been changed

Access to health professionals they could trust was an issue for several women. Lucy (22) indicated that she would like to see a woman GP:

I don't like speaking to men doctors. It (pill) helped a little bit but then went back to where it was before. My periods still hurt..... But I feel nervous talking to the doctor.

Prompted by the research interview, Lucy's advocate helped her write to her GP to ask for a review. Her pill was changed, and Lucy's period pains receded.

Conclusion

Our research suggests that how contraception is chosen and managed is worth further investigation. The majority of women we interviewed knew too little about contraception to make an informed choice. Information was hard to come by, parents, staff and GPs appeared as major influences. Despite known side effects of long term contraceptive use, basic health checks were rarely reported. In some cases women reported having been forced to use contraception and this had had a lasting impact on them. However, some women were able to make independent choices about sex and contraception. Contraceptive decision-making and choice for women with learning disabilities needs greater attention across a range of health and social care services. We made a number of recommendations for policy and practice as a result of carrying out the research:

- Improved access to sex education and information about contraception would help women with learning disabilities to make decisions about sex, pregnancy and parenting.
- More easy read information with pictures would be useful to help women make their own informed contraceptive choices
- It should be recognised by service providers that some women would prefer to speak to a female doctor or nurse and efforts should be made to facilitate this choice
- Closer monitoring and reviewing of contraception would help women to manage their contraceptive use more effectively
- Specialist advice and support should be available to women with high support needs who might also be more vulnerable to coercion.

To access the full report go to <http://www.open.ac.uk/health-and-social-care/research/shld/resources-and-publications/shld-reports>