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Contraceptive choices for women with learning disabilities

An Open University research project

Funded by Open Society Foundations (Grant No: OR2014-12989)



REPORT



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Executive summary

(a short summary of the project)

'Contraceptive choices for women with learning disabilities' is an Open University research project, supported by a grant from Open Society Foundations (Grant No: OR2014-12989). This inclusive project set out to explore women's contraceptive decision-making and sought to include women with mild to moderate learning disabilities as well as women with high support needs. Between December 2014 and April 2015 we interviewed 19 women living in several locations across the United Kingdom.

Key findings

- Knowledge and understanding of contraception vary and it is sometimes difficult to achieve a shared understanding of what contraception is.
- Contraceptive use is associated with sex, pregnancy and parenting and when women use contraception for other purposes it may not be recognised as such.
- Women report using contraception for a variety of reasons including the prevention of unwanted pregnancy and because they want to delay, or do not want to have, children. Some women use contraception to manage menstruation.
- Sometimes women are on contraception because they are not trusted or believed, or because they are thought to be 'at risk' of pregnancy and abuse.
- A few women make very independent choices about sex and contraception and others are supported to make contraceptive choices by family, friends, advocates and health and social care professionals.
- Some women do not receive suitable information or advice to make informed contraceptive choices and other people make decisions for them.
- Historically, some women have been forced to use contraception when it was not needed and these experiences have had a lasting effect on them.
- There is evidence that contraceptive use is sometimes effectively planned, managed and reviewed but in other instances this is not the case.
- Women appreciate staff who will listen carefully to concerns about contraception and relationships and support them to access the best contraception care.

Implications for policy and practice

- Improved access to sex education and information about contraception would help women with learning disabilities make decisions about sex, pregnancy and parenting.
- More easy-read information with pictures would be useful to help them make contraceptive choices.
- Sometimes women would prefer to speak to a female doctor or nurse and this should be respected.
- Closer monitoring and reviewing of contraception would help women manage their contraceptive use more effectively and may have longer term benefits to health.
- Specialist advice and support should be available to women with high support needs who are more vulnerable to coercion.

Implications for further research

- Little is known about the contraceptive choices of women with high support needs; but next to nothing is known about women who fall under Mental Capacity Act legislation in the UK. Urgent research is needed to explore their experiences.
- An inclusive co-research model is valuable but it should be acknowledged that it takes more time to work in this way.
- Working with sympathetic organisations to recruit respondents is essential.
- An easy-read illustrated questionnaire, or similar, is a useful tool in guiding conversations and it is helpful when this is shared with women (and/or support workers) prior to interviews.
- Researchers should be open to different ways of supporting women before, during and after interviews.
- Interviews should enable women to express their views freely but it can also be useful when women are supported to participate.
- A series of interviews with each woman should be conducted and interviews should be informal and relaxed, paying attention to language, location and ambience.

Background to the research

(why we are doing the research and how we got here)

Introduction

People like us don't have babies. No one in the centre does apart from staff. Some people have their stomachs taken out (Atkinson and Williams 1990: 175)

This quotation is taken from a women's group discussion in a day centre for people with learning disabilities in the 1980s. Although spoken over 20 years ago, the words of this young woman focus attention on a seldom discussed issue (Tilley et al., 2012): who makes decisions about contraception and reproduction when a woman is labelled as learning disabled?

Most adults, including many with a learning disability, want to be parents and people with a learning disability should be able to consider and discuss whether or not parenthood is a goal for them (Servais, 2006). Research has established that parents with a learning disability can, with the right support, care for their children well (Condor et al, 2010). Others choose not to become parents (Chapman et al., 2015).

Yet in relation to contraceptive decision-making many women with learning disabilities feel they do not have the opportunity to make their own family planning decisions. This applies to starting contraceptive use, duration of use and deciding to discontinue (McCarthy, 2009a; 2009b). Instead they report that decisions are imposed on them (Rowlands, 2011). Some women are assessed as unable to make their own decision about contraception and the involvement of others is required to make a 'best interests' decision on their behalf. For those involved in this sensitive task it is crucial that decision-making is undertaken in ways that uphold the autonomy, wishes and preferences of the individual themselves (World Health Organisation (WHO), 2014: 7).

Although there has been considerable research into issues concerning parents with learning disabilities (see Llewellyn et al., 2010 for a comprehensive overview of this literature), in the UK, aside from the work of a few (see for example McCarthy, 2009a; 2009b; 2010a; 2010b; Stansfield, 2007; Stansfield et al., 2007; Rowlands, 2011) far less attention has been paid to the question of how learning disabled women's reproductive capacity is managed (Tilley et al., 2012), and the associated processes of contraceptive decision-making. Contraceptive decision-making with women who have high support needs remains particularly under-researched (McCarthy, 2010: 294).

In 2010, drawing on a 40 year history of learning disabilities research, the Open University began investigating the issue of contraception for people with learning disabilities. The International Network on the History of Sterilisation was established and *The Secret History of Sterilisation* was launched on iTunes U, an audio podcast which explores the reasons behind sterilisation including the voices of survivors themselves. In July 2013, the Open University convened an international symposium to explore the issue of contraceptive decision-making with women with learning disabilities. Participants included a self-advocate, parents, academics working in the field, practitioners, policy makers and disability campaigners. Our focus was to explore emerging tensions between rights-based policy and the lived experiences of women with learning disabilities. UK and international policy emphasises the rights of women with learning disabilities to retain their fertility, to choose to have children, to access sexual and reproductive health services on an equal basis, and to be fully involved in decision-making about their lives (see, for example, the International Planned Parenthood Federation Declaration on sexual rights, 2008; UNCRPD, 2006; DH, 2009; MCA, 2005). However, participant accounts from a self-advocate, service manager and lead academics highlighted significant gaps between the policy picture and the way in which day-

to-day decisions about contraception were actually made with women labelled as learning disabled. At the end of a lively and productive discussion we concluded there was mounting evidence of a divide between rhetoric and reality. There was clear consensus about an urgent need for further research to interview women with learning disabilities and document their experiences.

In 2014, Open Society Foundations provided funding for an inclusive Open University team to achieve the following outcomes:

- Provide data on women's experiences of contraceptive decision-making
- Provide data on the experiences of women with high support needs¹
- Provide a methodological framework for including women with learning disabilities in research on their reproductive rights and experiences
- Strengthen the existing International Network on the History of Sterilisation, convened by the Open University.

The research addressed the following questions:

- Why do women believe they are receiving contraceptive care and what are their views about this?
- How have women made decisions about what sort of contraception would be useful to them?
- Do women feel they have been supported to make contraceptive decisions?
- Do women understand the possible side effects of the type of contraception they use?
- What support have women received to understand contraceptive care and its implications?
- What do women know about how and when they can stop using contraception?

The 2014 World Health Report highlights women with learning disabilities as a population vulnerable to inappropriate reproductive control. This research set out to firmly root the reproductive experiences of women with learning disability within the context of wider debates on human rights, reproductive justice and supported decision-making. To this end the study is well located within the international remit of Human Rights Initiatives supported by Open Society Foundations to promote justice, equality and participation of all. Work underway within the Open Society Foundations on disability rights, deinstitutionalisation and 'looking differently at disability and decision-making' is also highly compatible with the inclusive, rights-based approach that underpinned our research.

This report presents key findings from interviews undertaken with 19 women with learning disabilities about their experiences of contraceptive decision-making. The stories were gathered by an inclusive team of female researchers from the Open University who interviewed women across a range of UK settings. These previously absent voices (Atkinson, 1997) shed light on how

¹Following the work of Beamer and Brookes (2001) on supported decision-making, the project adopted the following definition: 'High support needs describes people who have learning disabilities and extra needs. Some have physical impairments, others have additional health care needs or behaviours described by services as "challenging". This definition could incorporate women with learning disabilities who have more complex health care needs, are wheelchair dependent or women who have experienced mental health difficulties. In the UK it would not include people with more profound disabilities who fall under Mental Capacity Act 2005 legislation.

contraceptive decision-making is experienced by women on the receiving end of policy and practice. This report sets out the literature on contraception and inclusive research that informed our approach, presents key findings and concludes by making a series of substantive, methodological and policy recommendations.

The project provided opportunity for women with learning disabilities to share their experiences of using a wide range of contraceptive methods. Women spoke about the information and advice they had received from family and staff about contraception and parenting and how this had influenced their decisions. These rich, experiential accounts enable access to a continuum of previously hidden experiences: from situations where women felt well-supported and empowered to accounts of situations where individual choice had been clearly overridden.

The research team brought together author interests in self-advocacy, inclusive research, women's groups and health promotion, oral history, life story approaches, supported decision-making, social policy and health sociology. A qualitative research design was developed with the aim of facilitating in-depth understanding of women's experiences of contraception. The project adopted an inclusive methodology that aimed to ensure women with learning disabilities were able to shape the research agenda, as well as be involved as researchers and research participants.

Background and context

There are important benefits to including people with learning disabilities in research, including the reduction of health, economic and social inequalities and the necessity of building on experiential accounts from people on the receiving end of policy and practice (McDonald and Kidney, 2012). As the international research community works to correct the past abuses of research participants, concerns have emerged that a protectionist mind set has taken hold, contributing to more conservative practice and posing new challenges for researchers working with people with learning disabilities (Iacono 2003, 2006; Boxall and Ralph 2009; 2010). Grove (2002, 2004) argues that deciding not to research with individuals who are deemed 'vulnerable' may actually increase their vulnerability because people will remain ignorant of their circumstances and treatment. Furthermore, exclusion from research may denude the knowledge base in respect of the health, welfare and quality of life of marginalised groups (Tuffrey-Wijne et al., 2008). As an inclusive research team we reasoned that both these arguments applied to the under-researched area of contraceptive decision-making and remained committed to our focus on accessing stories told by women with learning disabilities themselves.








This research builds on findings from an online survey run by the Open University between April and June 2012. The survey explored the views of third parties, including family members, advocates and health and social care practitioners with previous involvement in contraceptive decision-making. Within two weeks 90 responses were received demonstrating high levels of interest and concern about the subject. The form of contraception most commonly reported was contraceptive implant followed by the pill. 28 per cent of respondents said that contraception was required because the women concerned were sexually active, in 15 per cent of cases there was an expectation that that the women would become sexually active, whilst a fear of pregnancy and the need to manage menstruation were cited in 31 and 17 per cent of cases respectively. These figures from third parties appear to confirm McCarthy's (2009a, 2009b, 2010) earlier findings that contraception is frequently used 'just in case' without a clear clinical or social rationale for the benefits (Earle et al., 2012).

21 responses from the online survey were from third parties with involvement in contraceptive decision-making with women with high support needs. The highest number of responses in this group were from family members. The issue of contraception was reported to be raised at an earlier age with this group, with management of menstruation as the most common reason for the introduction of contraception. Fear of abuse, avoidance of pregnancy risk and an expectation that the woman would become sexually active were other reasons cited for starting contraception.

Findings from this research were accompanied by publications in the medical literature (Jeffrey et al., 2013) raising concerns that research on managing the menstrual problems of adolescents with learning disabilities and physical disabilities is limited and consequently there is a lack of evidence of best practice to guide clinicians in this area (2013: 107). Rowland's (2011) examined the application of Mental Capacity Act guidance to contraceptive decision-making and evaluated contraception methods in terms of the degree of restriction they impose on a person's rights and freedom of action, creating a continuum where condoms are viewed as the least restrictive and surgical sterilisation the most.

Following the international symposium convened by the Open University in Summer 2013 a decision was made to move forward as quickly as possible. Founded in 1994, the Social History of Learning Disability Research Group (SHLD) at the Open University has pioneered the development of a range of inclusive methodologies in order to influence learning disability policy and practice across the whole spectrum of health and social care agencies and personnel, from front line practitioners to senior managers and board members. The Research Group is internationally recognised, and has fostered partnerships with universities and advocacy organisations across Europe, the US, Canada, Australia, New Zealand and Japan. The group provided an ideal foundation from which to progress this study.

Why we are doing the research

	<p>Little is known about how women decide about contraception.</p>
	<p>In 2013 The Open University brought together people interested in contraception for women with learning disabilities.</p>
	<p>Everyone agreed it would be good for researchers to talk to more women about their use of contraception.</p>
	<p>Open Society Foundations gave the Open University some money to do this.</p>
	<p>Researchers interviewed 19 women with learning disabilities across the UK.</p>
	<p>This included interviews with women with high support needs.</p>
	<p>This report says what they found out.</p>

With thanks to Mencap for their kind permission to use the above images.

Review of the literature

(what is already know about the topic)

Process

As explained in the introduction, the purpose of the project was to speak to women with learning disabilities, face-to-face, about their decision-making and experiences around using contraception. In tracking 'What is already known about this topic', we have planned our review to incorporate historical and international material around eugenics and sterilisation based in societal values and beliefs about the personhood of a woman with learning disabilities. We reflect on policy and decision-making today on protection and parenting; issues around support and lastly the very little we know about the sex lives of women with learning disabilities. To reflect the inclusive process, Lou adds her comments and previous writings throughout the text in speech bubbles or banners respectively.

The review of what is already known about our topic is presented in the sections below. This follows point 2 of the 'research cycle' set out by the Carlisle People First Research Team in one of their articles about 'inclusive research'

(Carlisle People First Research Team, 2001)

Introduction

It is widely agreed that research and literature on the lives of women with learning disabilities are scant, and even more so in the areas of sexuality and contraception; the article by Tilley et al. (2012) sums up the position. We learn through the small amount of previous research that exists, that women's lives, particularly their sexual lives, are experienced in a largely silent penumbra.

Historical and international values

Historically and internationally, the experience of women (and men) with learning disabilities is bound up in institutionalisation, based on a eugenic societal fear of their procreativity and parenthood. This is a far reaching and embedded view, stretching as far back as the Ancient Greeks. Aristotle was a 4th Century B.C. Greek philosopher and student of Plato who believed that men were the most highly evolved beings, with women being an evolutionary step below. He recommended that there should be laws around preventing disabled children. He wrote in Politics, '...let there be a law that no deformed child shall live.'²

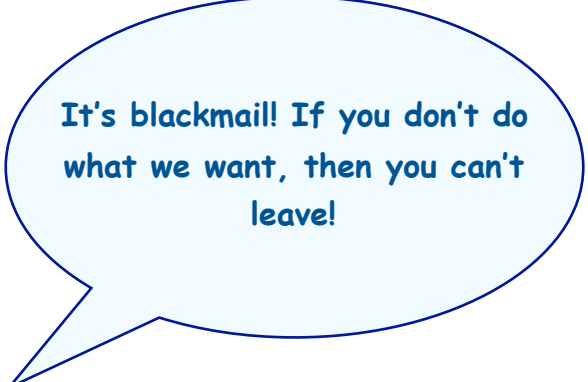
The legacy and impact of these ingrained cultural beliefs are explored in depth by Lee Ann Monk (2015: 46-64). She notes that much international policy has constructed people with learning disabilities as 'menace', or as Mary Dendy and her contemporaries remarked of feeble-mindedness: 'an evil which brings all other evils in its train' (cited by Monk, 2015: 48). It was taken that mental deficiency was an hereditary defect passed from one generation to the next which rendered people inclined to immorality, thus further linking people with learning disabilities into a range of other societal fears such as promiscuity, criminality and poverty (Goodman, 2005). Monk (2015) goes on to explain that the international policies introduced in the early twentieth

² See <http://mn.gov/mnddc/parallels/one/3.htm> (accessed 15/05/15).

century were based on imposing control, including (in the UK and many other countries), compulsory incarceration. As an example, Walmsley (2005: 58-59) points out that through the UK Mental Deficiency Act of 1913, '65,000 people were placed in colonies, hospitals or other institutions... with no legal right to petition against continued detention'. What happened inside these institutions is of prime importance to this topic.

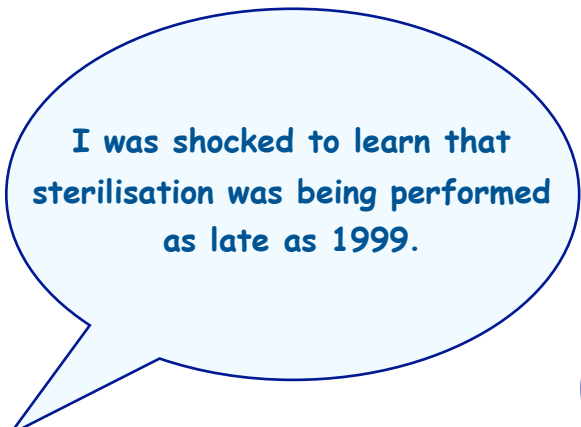
Management of sexuality through sterilisation

Many countries restricted marriage for people with learning disabilities as well as introducing compulsory sterilisation programmes, with the United States taking a pioneer position (Thomson, 2010: 120). By 1939 almost 31,000 people across 30 states had been sterilised (Monk, 2015: 50). Canada, Denmark, Norway, Sweden, Finland and Germany all followed suit introducing laws to sanction sterilisation, where the main target was the 'mental defective', believing the condition was passed through heredity. These practices carried on well into the middle of the twentieth century where sterilisation often became a precursor to release from the institution. Stefansdottir and Hreinsdottir (2011), cited in Tilley, Walmsley and Earle (2012: 49), report testimony from one of the Icelandic women, Ragnheidur, in their study: 'When I moved to the group home I had to undergo sterilization. I didn't agree but I had to agree because otherwise I would not be allowed to move from the institution'.




It's blackmail! If you don't do what we want, then you can't leave!

Although the UK did not introduce such legislation, there were still 'voluntary' sterilisations that took place 'under the radar' until quite recently, where the practice has been reframed as being of 'therapeutic benefit' (Dyer, 1987; Thomson, 1998).



I was shocked to learn that sterilisation was being performed as late as 1999.



I didn't realise that sometimes they went the whole hog and gave women a hysterectomy. That's disgusting!

Monk (2015) remarks that anxieties about reproduction impacted women with learning disabilities disproportionately, linking the pervading fears of promiscuity and 'hereditary defect'. In the early twentieth century, women with learning disabilities were said to be more 'fecund' than other women with 'unbridled sexuality', and thus 'morally defective'. Monk (2015: 51) also argues that, this being the case, women with learning disabilities were more likely than men to be institutionalised, for longer periods of time and more likely to be sterilised. Any women unfortunate enough to be deemed as 'morally defective' and incarcerated whilst pregnant would give birth to have their babies taken away and given up for adoption.

Some women were labelled as 'moral defectives'. They were rounded up, institutionalised, gave birth to their babies and were then cruelly separated from them. The babies went away for adoption and the women never saw them again.

(written by Lou Townson in Chapman et al., 2015: 27)

Tilley et al.'s (2012) article tracks the oral history of women who were sterilised, often without their knowledge, and the disastrous impact it had on their lives. They also make the point that we really need to understand a gendered view regarding issues of sexuality which has been surprisingly silent when it comes to thinking about current policy and practice.

Many women with learning disabilities have probably never even heard of the word 'sterilisation' let alone know what it means...

The fear of the unbridled sexual appetite and consequent uncontrolled reproduction of people with learning disabilities sits alongside another important notion present in much of the literature and subsequent policy today about the belief of 'eternal' or 'forever children' (Chapman et al., 2015: 153).

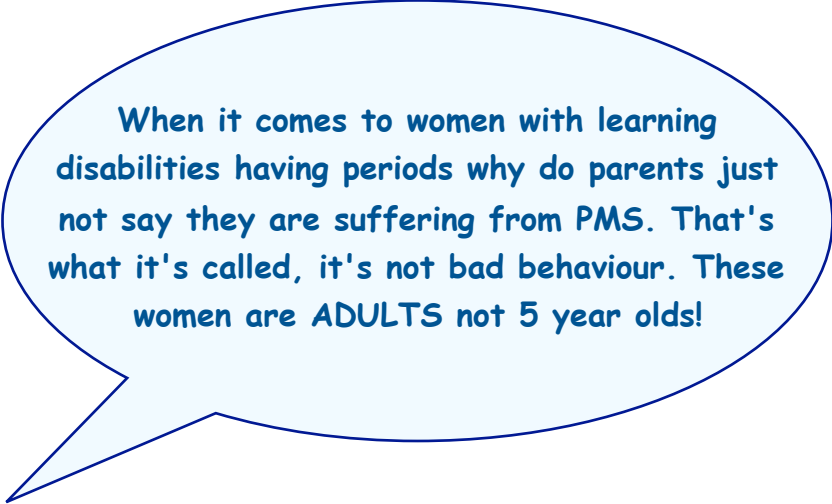
The 'eternal child'

The 'eternal child' idea generates from an historical and religious belief going back centuries that a person with learning disabilities is somehow blessed as a special type of person in need of protection (Williams et al., 2013). According to early Christian doctrine, people were encouraged to look after those considered 'sick and feeble' despite opposing and co-existing entrenched beliefs that disability may be a punishment (Otieno, 2009).

There are two very significant points about the idea of the 'eternal child' in relation to sexuality, set out at some length by Wolfensberger and Thomas, (1983: 25). The first point is that it ignores the rights of adulthood of the person with learning disabilities. According to McCarthy 1999: 53), 'Just as it was unthinkable to talk to young children about sex, so it was unthinkable to talk to adults with learning disabilities about sex – protecting their natural innocence was a priority and this fitted into

an “ignorance is bliss” philosophy’. The legacy of this view persists today in the constant citing of a person’s ‘mental age’ opposed to their chronological age, as well as tacit comments about having, for example, ‘the mind of a four year old’.

The second point links to policy actions that lead on from this point of view. In managing the sexuality of women with learning disabilities, medication can now be given to ‘arrest’ sexual development, using contraception to delay or manage periods, arguably a modern hidden form of sterilisation. The article by Tilley et al., (2012) cites the ‘Ashley case’ in which parents of a severely disabled child sought growth attenuation, including sterilization, to keep her in a state of permanent childhood (BBC news online, 17th January 2007). They further cite the research of Stansfield et al, (2007) which focused on the referrals for sterilisation made to the Official Solicitors in England and Wales between 1988 and 1999. They found that ten out of 73 referrals had been made on the basis of ‘menstrual difficulties’.



When it comes to women with learning disabilities having periods why do parents just not say they are suffering from PMS. That's what it's called, it's not bad behaviour. These women are ADULTS not 5 year olds!

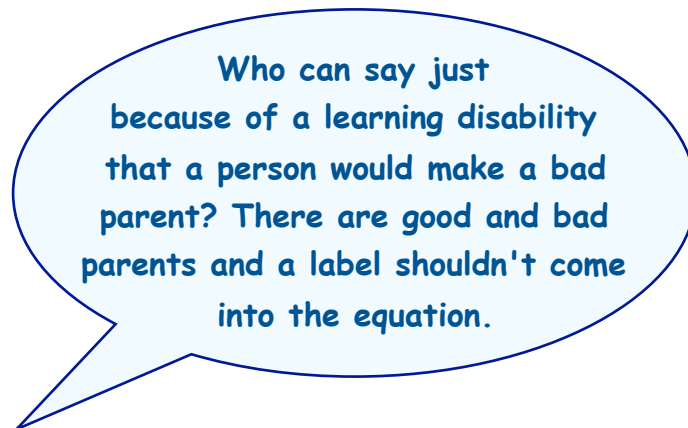
Management of menstruation in relation to contraception has been cited in a number of studies (see Chou and Lu, 2007; van Schroyen Lantman de Valk et al., 2011; McCarthy, 2009). McCarthy (2009) remarks from her own research that menstruation still continues to be a reason cited for the long term use of contraception for women with learning disabilities.

Overall the two recurrent yet paradoxical themes about the sexuality of people with learning disabilities linked to the notions explored above are of protection and control. Both of these stereotypes have provided rationales to prevent people from having sex and conceiving. Narratives in Chapman et al. (2015), demonstrate that the same anxieties about people with learning disabilities abound today, across different cultures, as in the past, and are driving contemporary policy interventions to protect and control. Now the days of incarceration are on the wane, it raises the concern that sterilisation and contraception alongside childcare proceedings are becoming the modern equivalent in our communities of earlier practices.

Parenting

Sexuality as a fundamental human right has come to the fore in the critique of the old institutions and practices, and through progressive legislation, yet there has still remained an assumption that procreation is a dire problem. Even where marriage has been advocated for couples with learning disabilities, these marriages have been significant in ignoring the idea of parenthood (May and Simpson, 2003). Wolfensberger (1972), explained that even where social-sexual fulfilment should be a right for all adults, it would in North America only be achieved through a childless marriage. This feature was also recognised in the pioneering work of the Crafts (1972) in advocating marriage. Thus, even where the right to sexual expression has been considered appropriate, the taboo of parenthood has remained controversial.

Additionally, there is research demonstrating that mothers of women with learning disabilities may be worried about the subsequent care of grandchildren falling to them (Tilley, Walmsley & Earle (2012: 54).



To bring this to date, it is possible that the use of long-acting contraception has replaced sterilisation as the 'acceptable' face of dealing with the problem of procreation by women with learning disabilities. This still reflects a societal fear, and is further demonstrated in the number of children removed from parents with learning disabilities. Currently, there are no clear or accurate figures of parents with learning disabilities but according to the Norah Fry Research Centre; worldwide research generally suggests that 30-40 per cent of parents with learning disabilities lose their children. There are further estimates that 40 to 60 percent of children in the UK are placed in alternative care (see <http://www.aboutlearningdisabilities.co.uk/becoming-parent-with-learning-disabilities.html>).

Further, in a 2014 study by Gilmore and Malcolm of doctors in New South Wales, Australia, it was found that the majority of doctors cited less sexual freedom as desirable for adults with learning disabilities compared to those without learning disability and were more cautious about parenting than other aspects of sexuality.

Sexual abuse

It could also be argued that the well documented prevalence of sexual abuse, particularly towards women with learning disabilities, has actually been tolerated far more than society's ability to tolerate the procreation and parenting of couples with learning disabilities (see Pring, 2005; Campbell, 1998; Brown and Turk, 1992). New figures released in May 2015 demonstrate that almost 5,000 disabled adults have been sexually abused in England over the past two years, and of that figure, two-thirds related to people with learning disabilities (Derbyshire, 2015). This resonates with earlier research by McCarthy (1999). She found that 14 of the 17 women she interviewed in her study of sexuality and women with learning disabilities had experienced sexual abuse of one kind or another and that several had experienced multiple acts of abuse. Later research by Chivers and Mathieson (2000) on training in sexuality and relationships in Australia corroborates these findings.

At a women's conference run in a Northern city a few years ago, Chapman and Townson were witness to testimony about the seeming brutality of some of the women's sexual relationships. As Lou recalls:

Landman (2010) also points out that many people with learning disabilities say they feel very isolated and lonely and it is therefore possible, '...that it is the primacy of the relationship that is often more important than what is happening within it'.

Many of the women talked about their own relationships with men and partners. Some of the women didn't realise that what they were experiencing was actually abuse; they had assumed it was a natural part of a relationship. A lot of this confusion seems to come from a lack of useful sex and relationship education. As the lives of women with intellectual disabilities can be very monitored and protected, these women were not experiencing the same life opportunities that other women benefit from.

(written by Lou Townson in Chapman et al. (2015: 164)

Rights and decision-making

The United Nations Convention on the Rights of Persons with Disabilities (2006) was ratified by the UK Government in 2009. The Convention states that all disabled people should have their human rights met on the basis of equality with non-disabled people. The Convention is also available in an easy-read format, understanding that communication may pose difficulties for some. The Convention is based on a social model understanding of disability, that people are disabled by the way society works rather than by their individual impairment. This is an important move in trying to understand issues around reproductive rights where, historically, other people have been able to make key decisions about a person's reproductive future, rather than the person themselves.

The research available demonstrates that decisions around sex and contraception, continue, for the most part, to be taken by others, mainly parents, carers and professionals (Fitzgerald and Withers, 2013). We know that staff are employed to provide essential support to people with learning disabilities but, according to Gravell, (2012) this support can often verge on being authoritarian. It is difficult for people with learning disabilities to obtain information both in terms of sex education and of the law pertinent to their sexual rights. O'Callaghan and Murphy (2007) found that only 20 out of 60 people with learning disabilities knew they had a legal right to marry and only 50 per cent realised that the law relating to sexual assault and rape also applied to them. Additionally, information around diversity in sexuality relating to being lesbian or transgender is even more difficult to access (Chapman, Ledger and Townson, 2015: 158).

In her study of 23 women with learning disabilities taking contraception, McCarthy (2010a) found only five reported that they had made the decision to take contraception and in fact it was the parent, carer or GP that tended to make the decision. Of these women, they tended to be starting contraception earlier and were ending it much later than other women, leaving them open to a plethora of potential side effects. McCarthy (2009) described this as the 'just in case' approach and also notes that ethical, moral and human rights issues do not disappear simply because reproductive technologies change. She states: 'when a woman... is put on contraception for most or all of her reproductive life this is arguably a chemical sterilisation, yet it has no legal scrutiny' (McCarthy, 2010b: 264).

Contrasting this to current rights, the Interagency Statement from the World Health Organisation (WHO, 2014: 5), entitled, 'Eliminating Forced, Coercive and Otherwise Involuntary Sterilization' states that:

Women with intellectual disabilities are often treated as if they have no control, or should have no control over their sexual and reproductive choices; they may be forcibly sterilised or forced to terminate unwanted pregnancies, based on the paternalistic justification that it is 'for their own good'... Human rights organisations have recognised

[this] constitutes discrimination, a form of violence or torture, or other cruel, inhuman or degrading treatment...

Summary

Tilley, Walmsley and Earle (2012: 55-58) point to three main reasons why sterilisation, and later contraception, may have been regarded as 'acceptable' by those who make decisions in the lives of women with learning disabilities:

- (a) Societal fear around people with learning disabilities becoming parents, linked with subsequent problems of care-giving following the conception and pregnancy of women with learning disabilities, where care duties were likely to fall on the mothers of those women.
- (b) The prevalence of sexual abuse amongst women with learning disabilities; where parents and carers may seek surety that any instance of sexual abuse will not result in pregnancy.
- (c) Management of menstruation (which has been cited in a number of studies above).





Given the backdrop of power and control taken away from women with learning disabilities, the importance of talking to women themselves cannot be overstated. Women with learning disabilities are often portrayed as victims, armed with little formal knowledge of their physicality or rights (Hassouneh-Phillips and Curry, 2002). The precarious and delightful nuances of the experience of romantic love and sexual satisfaction are largely documented as fleeting, if not missing (Blyth and Chapman, 2015). This research seeks to focus on the views of women with learning disabilities to understand their own thoughts and views and volition.

Clearly there is a lot of work to do around including women with learning disabilities in education and decision-making about their sexual and contraceptive choices. The WHO (2014: 10) point out that in order for women to make good decisions in their sexual lives, there should be, 'comprehensive information, counselling and support should be accessible for all people'. Practical ways of addressing this are to use accessible materials and to provide relevant and reachable sex education, as set out in the tables and appendices of Chapman et al. (2015: Chapters 2, 11 and appendices) and something we return to in our findings.

What we already know about contraceptive choices



What do we already know about women with learning disabilities and contraception?

	<p>There is very little research about this</p> <p>Not many researchers talk to women themselves</p> <p>Women with high support needs are mostly ignored</p>
	<p>History has been unkind to women with learning disabilities</p> <p>They lived in institutions</p> <p>Many were sterilised</p>
	<p>There are rights for women with learning disabilities</p> <p>They have rights to have sex</p> <p>They have the right to a family life</p> <p>This is not often said</p>
	<p>It is important to find out what women with learning disabilities think</p>

Research methods

(the research activities used to explore the topic)

Introduction

The project focus was on the perspectives of women with learning disabilities. It built on an online survey about contraceptive decision-making for women with learning disabilities which collected the views of third parties (Earle et al., 2012). This project used a different methodology, face to face interviews, more appropriate to accessing the views of women with learning disabilities.

The Research Team sought to interview at least 15 women with learning disabilities about their experiences of contraception, including women with higher support needs who are under-represented in the literature to date, and whose experiences the online survey found were likely to differ from those of women with milder disabilities:

- Likely to start contraception earlier
- Less likely to have been involved in any way in decision- making
- Menstruation management as the stated reason for administering contraception. (Earle 2012, Ledger et al., in press)






It was our intention to facilitate the participation of women with more complex needs using whatever means possible. It was anticipated that some women would require support from an advocate, family member, paid supporter or similar, to enable them to participate. To enable the inclusion of women who use fewer words to communicate the team planned for the use of circle of support interviews involving family members, friends and members of staff alongside traditional 1:1 formats. Using purposive sampling it was also our intention to reflect difference and diversity with respect to background and life circumstance.

The research team

The aim of this project was to hear directly from the voices of women with learning disabilities about their contraceptive experiences, which built on earlier research collating the views of parents, carers and professionals. In particular, the project aimed to be inclusive and to ensure that women with learning disabilities were able to shape the research agenda, as well as be involved as researchers and research participants. To this end Lou Townson was employed as a co-researcher alongside Rohhss Chapman. She and Rohhss worked together as co-researchers (see Walmsley and Johnson, 2003) as well as working with the wider team. The research team comprised five people, all of whom had worked together on previous projects³. Here they are:

³ For logistical reasons two other people also interviewed and we discuss this below.

The research team

	<p>Susan Earle, Principal Investigator <i>Associate Dean Research, The Faculty of Health & Social Care, The Open University</i></p>
	<p>Rohhss Chapman, Co-investigator <i>Independent Researcher, Carlisle People First Research Team Ltd</i></p>
	<p>Sue Ledger, Co-investigator <i>Research associate, The Faculty of Health & Social Care, The Open University</i></p>
	<p>Lou Townson, Co-investigator <i>Independent Disabled Researcher, Carlisle People First Research Team Ltd</i></p>
	<p>Jan Walmsley, Co-investigator <i>Visiting Professor, The Faculty of Health & Social Care, The Open University</i></p>

This is how Rohhss describes their working relationship:

A note on inclusive research

The position taken by the Carlisle People First Research Team, is that ‘there is no part of the research cycle that cannot be made accessible’ (Townson, McCauley et al., 2004; Chapman 2014).

A co-research model

Louise was recruited for the contraception project. Later there were discussions from the team with me about whether I would be involved as a supporter to Lou. I was very interested in the project and glad to be asked.

We talked about the contraception project based on our previous experiences of working together on research over the past 17 years. We do not have a clearly defined researcher/support relationship as we have found the relationship to be dynamic and porous. In our research company, Carlisle People First Research Team Ltd (CPFRT), we all have an ostensibly equal role. We are all Directors of our company and make decisions together, even though people who do not have the label of learning difficulty are mindful to step back and allow others to speak first. Our work may be better described as a co-research model.

The decision was taken to employ us as co-researchers and for us to share the allocated funding. To be honest I did not ever want to work as a support worker to Lou. It seems inappropriate to use that formality as we are friends and colleagues and have worked as co-researchers many times before. It would be like stepping backwards to a place we started from and then developed and grew out of.

The term inclusive research was originally used by Walmsley and Johnson (2003) in their book on the topic. They explain the term is used to cover a range of approaches. These various research approaches closely connected to disability research which emerged from the disability movement. Mike Oliver, a prominent disabled academic, who was intrinsically involved in the emergence of the disability rights movement in the UK, urged that research around the lives of disabled people should be:

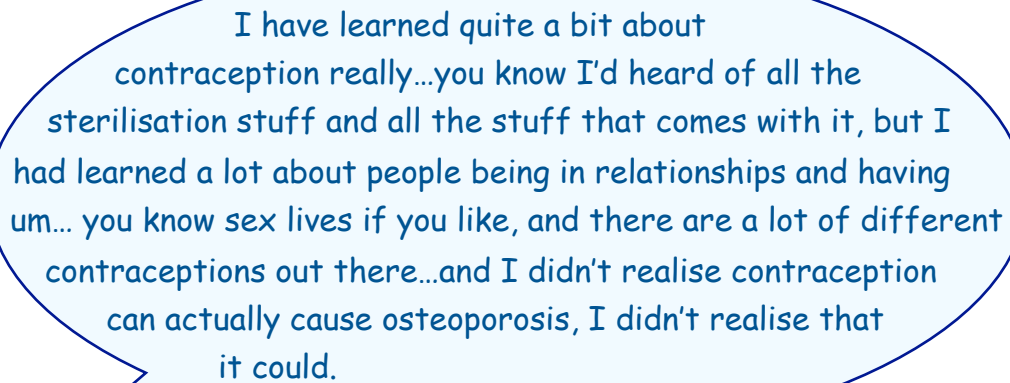
...both more relevant to the lives of disabled people and more influential in improving their circumstances. The two key fundamentals on which such an approach rests are empowerment and reciprocity. (Oliver, 1996: 141)

This was in contrast to what was perceived as 'traditional' approaches to research where disabled people were objectified by non-disabled professional 'experts'. Walmsley and Johnson (2003: 10) accept there are many definitions and processes involved under the umbrella of inclusive research but that, 'the term ...has the advantage of being less cumbersome and more readily explained to people'. Inclusive research is a collection of a range of the more specific approaches set out below:

- (a) Emancipatory research - where people with learning disabilities take ownership and control of research funding and processes and where research is undertaken to the advantage of disabled people (see Oliver, 1997; Priestley, 1999; Zarb, 1992).
- (b) Participatory research - where people with learning disabilities may (or may not) be part of the research process, are involved in some manner, but do not 'own' the research (see McClimmens, 1999; Chappell, 2000; Ramcharan et al., 2004).
- (c) Action research - where people with learning disabilities may not own the research but could benefit from the process of improving practice or organisational working (see Stevens and Folchman, 1998; Ward and Trigler, 2001).
- (d) Collaborative research - used by members of the CPFRT. For the team, 'collaborative research' describes formulating ideas together, bringing skills together in accessible

ways and, as far as possible, remaining fully informed (see Chapman, 2014; Chapman and Townson, 2013; Costly et al., 2010:103).

This project used collaborative research in the sense that Lou and Rohhss were employed as co-researchers and Lou took full part in discussions during the duration of the project. Commentary on the co-research experience is provided throughout this section. This is what Lou said about being involved in the research:



I have learned quite a bit about contraception really...you know I'd heard of all the sterilisation stuff and all the stuff that comes with it, but I had learned a lot about people being in relationships and having um... you know sex lives if you like, and there are a lot of different contraceptions out there...and I didn't realise contraception can actually cause osteoporosis, I didn't realise that it could.

Lou and Rohhss undertook a review of the work at the end of the project. This is what was said:

Working in the team as a co-researcher

Lou: I have learned a lot like, on the phone call today, you know when Sarah was explaining that analysis thing....

Rohhss: You mean NVivo?

Lou: Yeah NVivo, and you know I felt like, even though I didn't say, 'can you explain that to me?' You know she just explained that to me anyway which I thought was really good. And when I said, 'You mean like putting something into Google?' and she said, 'exactly!' And you know...I feel, I have felt from everybody who has been on the team like Sue and Sarah and Jan and obviously you, I have felt included in that way because I am asked what I think really, I seem to be and I'm going to be...a positive thing for me, I seem to be included more from other academics than from people you go and talk to about a project.

Rohhss: So you felt more included by the team than you did by say, Colin (a supporter from one of the advocacy groups)?

Lou: Eh I did, I did; I've got to be honest...

Selection criteria

Criteria for including women were:

- have a label of learning disability, and have been users of specialist services for people with a learning disability
- able to consent to take part without undertaking a formal assessment of capacity
- are using, intending to use, or have used contraception.

As we will show in the Chapter, the third of these simple criteria was less simple in practice.

In addition, as we had committed to including women with higher support needs we were seeking to include at least three women with higher support needs, defined as people who have learning disabilities and extra needs. Some have physical impairments, others have additional health care needs or behaviours described by services as 'challenging'. This definition follows Beamer and Brookes (2001) and can include women with learning disabilities who have more complex health care needs, are wheelchair dependent or women who have experienced mental health difficulties. In the UK it does not include people with more profound disabilities who fall under Mental Capacity Act (2005) legislation.

Project information

The team used an easy-read illustrated information sheet alongside one which was not so easy to read. The easy-read version was used to make contact with intermediaries and allowed them to explain to women with learning disabilities so that they could give informed consent (see appendix 2).

Consent

Informed consent was vital. An easy-read sheet was developed, to be used with the Information Sheet. Given the challenges of obtaining formal ethical (HREC) approval to interview women whose capacity to give informed consent was in doubt, the project was confined to women who, in the opinion of the team, relatives and/or support workers, were able to give informed consent.

Most consent forms were completed in advance by women supported by intermediaries. In six cases, consent forms were completed at the end of the interview. With these women a staged approach to consent (Grove, 2004; Ledger, 2012) was adopted. For women who had expressed an interest in being interviewed the 'getting ready for interview questions' PowerPoint presentation (see appendix 1), accessible information sheet and accessible consent forms (see appendices 2 and 3) were sent to them and a member of their support circle three weeks in advance of interview. The women and their supporter went through the consent form prior to interview and confirmed with the researcher that they were happy to go ahead with participation in the project. At the start of the interview the researcher checked with the women that they had seen the consent form and talked through it to ensure that the contents were understood. At the end of the interview the consent form was again discussed in relation to the interview content and the women were asked to sign. On two occasions using this process the women asked for specific pieces of text to be excluded or names anonymised. One woman asked to listen to her interview on the Dictaphone after signing the form. After she had listened to the interview she said she was pleased with what she had said and again confirmed her consent.

It is worth noting that whereas services were very aware of the importance of capacity to consent (as defined by the Mental Capacity Act 2005), this was considerably less formalised when working with advocacy organisations or individuals.

Recruitment of interviewees

This was the most challenging part of the research. The purpose of the research was to meet directly with women with learning disabilities to understand how they had experienced

contraceptive decision-making. There are concerns that adults with learning disabilities may be needlessly excluded from research (Iacono, 2006; Lai et al., 2012) or at a greater risk of being subjected to harmful research (McDonald and Kidney, 2012). People with high support needs may be at particular risk of research exclusion due to concerns about demonstrating informed consent (Ledger, 2012) and difficulties in obtaining ethical approval for inclusive methodologies (Boxall and Ralph, 2009; 2010).

One reason for exclusion may be that researchers find adults with learning disabilities more difficult to recruit. They rarely respond to open advert for participants due to literacy issues. Researchers have to rely on multiple gatekeepers who may choose to adopt a protective position rather than allow for the dignity of choice or risk (Walmsley, 1993). Some gatekeepers may resist participation for fear that services may be negatively evaluated or believe that they know the interests of the individual. There are also concerns that researchers attend too little to promoting research-related benefits for adults with learning disability.

Relationships, sex and the use of contraception for people with learning disabilities remain sensitive and often divisive topics (Chapman et al., 2015). Previous research highlights substantial difficulty in gaining access to interview people with learning disabilities about issues appearing far less sensitive than contraception. Carlisle People First Research Team, when seeking to access the experiences of people with learning disabilities during World War Two, reported that gatekeepers - staff and managers - sometimes declined interviews on behalf of people on the grounds that the 'subject would be too upsetting' (Dias et al., 2012).

In the UK recruitment of participants for this research coincided with substantial media interest in the sexual abuse of vulnerable individuals within care settings in response to two national inquiries (NSPCC/MPS, 2013; Jay, 2014). We moved forward in the awareness that this may heighten concern on the part of managers, front line staff and families.

Thinking about gatekeeping influenced our research design. In order to reduce the impact of gatekeepers on recruitment of people to take part, we incorporated into the research design the building of relationships with organisations prepared to invest time to support women in their involvement in our research. This was particularly important to support the involvement of women with more complex needs, likely to be more reliant on staff to facilitate participation.

With this in mind, it was anticipated that women would be recruited through the following channels:

- women who had contacted the team as at the time of the online survey on contraception for women with learning disabilities
- self-advocacy and advocacy groups known to the research team
- a service provider organisation (Zamma) with which the research team was in dialogue about the research
- personal connections with individuals.

All these channels were used. In addition, some contacts were made through snowballing, for example, Mary's family advertised it to people known to them. Nevertheless, recruitment of interviewees proved to be more challenging than anticipated. Reliance on intermediaries to explain the research did at times present a barrier. This extract from Rohhss and Lou's research diary illustrates some of the frustrations:

Given that recruitment was one of the most problematic areas in the project, details of how recruitment took place are included.

A diary extract

Some plans were thwarted. We wanted to go ourselves to explain in two specific parts of the region, but in both cases they insisted it had to be done by them – and neither worked out. If we had been allowed to go there to explain initially, we may have had better luck as I think we could have made it sound really interesting for the women to be involved. Having said that we did only get one interview through explaining at meetings and then it snowballed out so I guess we will never really know.

Women who had already contacted the team

Initially the team made contact with people who had expressed interest in taking part at the time the online survey was launched over 2 years previously. It had not been possible to interview them at that point as ethical approval had not been sought for including women with learning disabilities.

Two contacts responded when we publicised the project through email. One, Pauline, spoke on her own behalf. The other, Janine, was Director of an Advocacy Group (called C Advocacy in the Report) which had recently run a course on women's health.

Pauline was the first person to be interviewed, and this interview was used as a pilot. Pauline is very able. She drove her own car to the interview through London traffic. She said of herself:

When I was 50 they decided I was dyslexic. They did not pick this up at school. I wonder if all I have is dyslexia. To me, driving and learning disability don't really go together.

Despite this, Pauline had difficulty with recall, and this pointed in the direction of a more structured illustrated interview schedule; this was developed by the team following this pilot (described below).

Arrangements were made to meet and interview six women through C Advocacy Group in January 2015, in a distant part of the UK requiring pre-booking of travel. Two days prior to the scheduled date the Advocacy Director informed the team that there would be 12 women attending, not the expected six. All had signed consent forms. This necessitated a change of plan. Given time constraints the Director offered to help by interviewing some of the women. The illustrated questionnaire was sent in advance so that she could familiarise herself with the questions.

In the event all 12 women joined a group discussion during which the interview questions were shown. Six of these then agreed to a one-to-one interview on the day. Another young woman, who had been unable to attend due, ironically, to period pains was interviewed the following week via Skype. She was accompanied on the call by an advocacy worker from the same organisation.

A total of eight women were recruited through these contacts.

Recruitment through advocacy and self-advocacy groups

Members of the research team had contacts with 4 self-advocacy groups who were approached to advertise for interviewees. Of these, only two, NRA and PAP agreed to support the project. Of her approach to a self-advocacy group where she she knew two women well, Jan wrote:

I asked Tracy if she would be willing to be interviewed, or knew anyone who would be. She had previously been keen to meet researchers about diabetes. She changed the

subject rapidly. Something very similar happened when I asked Pat. At this point I realised this was not going to be as easy as I had hoped.

The process of recruiting interviewees through NRA is described in the research diary kept by Lou and Rohhss (as co-researchers). It took several months and illustrates the role of gatekeepers.

The role of gatekeepers

The first meeting with a worker took place at their offices. The worker suggested the project details could go on the newsletter given to members and that the workers in the area would be asked to give over some time to allow anyone who wanted to be involved to participate. It was to be brought up at their team meeting. But nothing came from this outside of one specific area, despite many follow up calls made by Lou and requests made by myself.

Eventually a meeting was set up for us to go to explain about the project. It was on a winter's evening and only one person turned up. She was a new member of our own research team and, after going through the information with her, agreed to be interviewed at a later date. It turned out that the lack of members at meetings was not about our project but about a general problem this advocacy group was having with engagement of members in meetings. We arranged to attend another meeting a few weeks later where facilitators would be present. Again we would talk about research and then mention the project and see if we could recruit.

At the second meeting more people turned up with their support workers. It was a mixed group of men and women and we were 'slotted in' as part of the agenda. There was discussion about research in general and the contraception project. Lou and I took it in turns to give information about it.

Afterwards a member of staff from a home phoned to say they had been going over the information given out at the meeting with someone who was interested. We discovered this was another lady we already knew, Elaine. However she did not meet the criteria of using or planning to use contraception although she had a very harrowing history concerning sexual abuse and rape.

The other meetings we had were separate pre meetings with Susan, Patricia and Deborah. We had a coffee and went through the details of the project, what would be asked - and left the women with the consent forms to look through. This means each person knew what was to come and could think about it before the actual interview.

In the other advocacy group, PAP, the worker agreed to ask women if they would take part, using the illustrated information sheet. Two women agreed. The advocacy worker was to prepare with the women, using the questionnaire. However, in the course of preparing for the interview one woman disclosed a safeguarding issue. The investigation was scheduled for the day the researcher had arranged to interview, involving both the woman and the worker. The other volunteer, Chloe, was interviewed and recorded by the advocacy worker three days later, as the Open University researcher was unable to return on a different day.

Four interviews in total were secured through contacts with self-advocacy groups.

Recruitment through a community service provider (Zamma)

Zamma is an inner city based organisation that provides housing and social care support to approximately 120 people with learning disabilities. It employs 225 staff in settings across a large city. The organisation is strongly committed to the fullest participation of people with more complex support needs, in all areas of practice development. The board presentation raised organisational awareness of contraception with board members feeding back that they were currently unsure of patterns of contraceptive use and decision-making amongst their female tenants as such issues were generally supported at an individual service level.

There was intense liaison between Sue and Zamma's senior staff to agree a protocol for contributing to the research, and to plan the best way of informing women about the research and enabling those interested to take part. As organisational resources would be required to support participation formal board approval was required for the research. The table⁴ describes the process in detail.

In the event four interviewees came through Zamma. All Zamma interviewees worked with a keyworker who knew them well to prepare for the interview using the illustrated questionnaire. Interviews were attended by the woman herself, and two senior managers in Zamma. Both senior managers had worked within the organisation for over 25 years and so knew all the women well. Interviews were informal. Three were set up in a cafe style with drinks and cakes to make the setting more relaxed. The other interview took place in the woman's own flat which was again very relaxed.

The Zamma process

Date	Activity and process
Nov 2012	Organisation expresses interest to the OU research team in supporting participation in research into sex and relationships.
September 2014	<p>Zamma has an inclusive management board. People with learning disabilities serve as members contributing expertise alongside other professionals including a public health doctor.</p> <p>OU researcher works with Zamma Chief Executive (CE) to prepare presentation about the research.</p> <p>CE presents paper and easy-read information about the project to the board for approval. The board approve the research and specifically approve facilitating the involvement of women with HSN. The board agree the use of resources to publicise the research and fully support tenants who wish to participate.</p>
January 2015	OU researcher and CE meet to plan how organisation will support interviews.

⁴ Easy-read version in appendices prepared for Board feedback.

Feb 2015	<p>Care Service Manager (CSM) in organisation writes to all tenants explaining the aims of the research and asking women with learning disabilities if they would like to take part. All managers are briefed about the research and asked to make sure that all women eligible for the study are told about the research and asked if they would like to participate. The invitation is headed with Zamma logo making it clear to tenants that this is a trusted project that the organisation are fully supporting. Easy read information prepared by the OU team is circulated via managers.</p> <p>CSM asks all home managers to identify women with high support needs within their service who have recent experience of using contraception and, drawing upon a supported decision-making model, explore with individuals and their circle of support if they would be interested in participating.</p>
March - April 2015	<p>Four women come forward expressing an interest in being interviewed for the project. Three women who currently fall under the MCA are identified for inclusion in further research.</p> <p>Interview dates are scheduled and three weeks before interview each woman is sent a 'getting ready for interview accessible PowerPoint' with the interview questions to enable people to prepare for meetings and to give further clarity to individuals and their circles about the research.</p>
April 2015	The organisation reports that it is unable to identify any women with high support needs who can consent to participation. This is unanticipated and the organisation begin analysing why this is the case. This exercise generates further data about contraceptive use and review for the study.
Mid-April 2015	Researcher meets with senior managers and Board member to review progress and agree work for completion by end of fieldwork (end April).
22 April 2015	<p>Final week of fieldwork-researcher writes to CSM to follow up final actions</p> <p>All interviews completed, anonymised and transcribed for analysis.</p>
26 April 2015	Organisation returns all information for analysis.
May 2015	Researcher writes to each of the women interviewed thanking them for their contribution and that an easy-read report of the research findings will follow later in the year via the Zamma CSM.

Recruitment through personal connections

When it became clear that more interviewees were needed to fulfil the commitment to include at least some women with high support needs, members of the research team contacted people they knew, and asked individuals working within services and advocacy groups to suggest people who might wish to take part.

A mother who had previously taken an active interest in the research volunteered to be interviewed with her daughter who has high support needs. Mary, who does not use speech to communicate, was interviewed with both her parents. One of the research team (Sue) contacted Yvonne, whom she has known since 1993. Sue asked Yvonne if she wanted to be interviewed and Yvonne agreed.

In total, two interviews were secured through personal connections.

Unproductive recruitment

A total of 12 organisations including health, social care and advocacy groups, were contacted in an attempt to find respondents. Despite repeated attempts at communication and negotiation, this did not yield any results. We have decided to record this aspect of the process because this illustrates the important role that gatekeepers play.

Through snowballing, we were approached by two advocacy/campaigning organisations to take part. Both initially seemed enthusiastic, however follow up calls and emails with one did not elicit a response. Contact with the second, NW, continued for several months. An appointment was made for Lou and Rohhss to go to explain the project to six women who had expressed interest. It was called off at a late stage. The explanation was that the women had changed their minds. Here are Lou and Rohhss's reflections on this frustrating process:

Frustration with recruitment and gatekeeping

Rohhss: Okay - what about what happened with NW then?

Lou: Well... I feel quite speechless about that really.... Because to me, is it people themselves? I mean I'm going to be blunt Rohhss..... why do people, you know, from NW, why do they have to contact people themselves and through the carers and support workers?

Rohhss: Like.. why didn't they allow us to come over and speak to the women about the project?

Lou: Why didn't they allow us? Which we said we would do...why didn't they allow that? And you know, they kept saying, ' oh we haven't heard from people's carers....well I'm very suspicious of that – there were a few people interested... then they said nobody was, was it the women themselves who weren't interested or people telling them not to be interested? I think what annoyed me with that.... that day we were set to go weren't we...I'd arranged not to have my one-to-one care that day!

Rohhss: Yeah, you had rearranged things.

Lou: Yes I'd rearranged it all... but I just kept it as it was instead of changing it back. But that I'd sorted it out in the first place and then they didn't really let us know till very late not to go... it was like we were left hanging in the air really...

This process illustrates the complexities of arranging to interview about a complex and sensitive topic through third parties with whom the research team did not have an existing relationship.

Recruitment of women with higher support needs

The most challenging aspect of the recruitment process was finding women with higher support needs. Following the work of Beamer and Brookes (2001) on supported decision-making the project adopted the following definition: 'High support needs describes people who have learning disabilities and extra needs. Some have physical impairments, others have additional health care needs or behaviours described by services as "challenging"' (Beamer and Brooks, 2001). It does not include people with more profound disabilities who fall under UK Mental Capacity Act legislation.

Women with high support needs are much less likely to respond in their own right. We were reliant upon intermediaries to both identify and then to approach women who met this definition. Although we approached numerous people known to the team within service provider organisations, none was able to help. Zamma tried, but of the 16 women with high support needs whom they are currently supporting none had used contraception recently.

Five campaigning and provider organisations, when approached about the recruitment of women with higher support needs, replied very positively about the need for the research and emphasised their commitment to supporting women in their networks to participate. In a number of cases advocacy workers worked in their own time to visit women and inform them of the research. One

highly committed advocacy worker approached six organisations in her locality on our behalf with access to over a hundred women yet this yielded two interviews, one of which had to be cancelled due to disclosure of a safeguarding issue whilst preparing for the research interview.

In a number of agencies the practicalities of setting up interviews about contraception proved challenging, with permission needed from internal panels and managers in order for us to gain permission to communicate directly with the women and their families to inform them about the study. Time was spent preparing information packs about the study for organisations to consider with follow up emails remaining unanswered.

For other organisations resources to support interviews within the fieldwork period were the issue, as we report below:

It is really great that this is being looked into. Staff have been raising concerns about many of these things. Our problem is that anything like this has to be run past managers first and that can take a couple of months. (Day centre worker)

We all want to support this research. The Chief Executive is really enthusiastic but we are under real funding pressure at the moment and have to give that priority. We are not sure if we will be going in two months. (Advocacy worker)

In the end four women with higher support needs were found through personal contacts (Mary and Yvonne) and C Advocacy (Chloe and Harriet) who appeared to meet the criteria but had not been labelled as such. Another woman came forward, but although she had had several boyfriends had not used contraception, so did not fit the eligibility criteria.

Diversity

Other than a specific commitment to recruitment of women with high support needs, we looked to have a diverse group of interviewees. The struggle to find women to involve did not permit us the luxury of specifying any further detail. Nevertheless, we did recruit a diverse group of people. They were from different parts of the UK, urban and rural, living with parents/family, living independently and living with support, and a wide range of ages. There were three BME women.

The interviewees included women currently using contraception, and women who used it up to 30 years previously.

The interviewees

After six months, interviews with 19 women had been recorded, four of whom have higher support needs according to the definition adopted. Details of the interviewees and the format of the interview are shown in the table.

Interviewee details

	Interviewee	Age	Interviewer	Location	Format	Notes
1	Xanthe	28	Sue	Supported living flat	Interviewing with keyworker and two Zamma managers (info 3 weeks beforehand) Informal coffee table style interview	White British
2	Chloe	43	Advocacy worker	Cafe	Advocate interview	High support needs White British
3	Yvonne	56	Sue	Her flat	One-to-one (info 3 weeks beforehand)	High support needs
4,5	Anne Louise	40 32	Sue	Supported living unit	One-to-two interview with supported living unit manager and 2 Zamma managers (info 3 weeks beforehand) Informal circle with food and drinks	Philippino (Anne) Black British (Louise)
6	Freda	36	Sue	Lounge of supported living Unit	Interviewing with supported living unit manager and 2 Zamma managers (info 3 weeks beforehand) Informal circle with food and drinks	Asked to be interviewed without other tenants present Black British
7	Patricia	54	Rohhss	Cafe	One-to-one interviewing (info 1 week beforehand)	White British
8	Susan	49	Rohhss	PF Office	One-to-one interviewing (info 1 week beforehand)	White British
9	Mary (with parents Eileen & Alan)	19	Rohhss & Lou	Mary's home	2 interviewers interviewed a family	High support needs White British
10	Deborah	29	Rohhss & Lou	PF office	Two-to-one interview (info 1 week beforehand)	White British
11	Patsy	51	Advocacy worker	C Advocacy Office	Group; individual interviews; followed by group interviews	White British

12	Monica	26	Advocacy worker	C Advocacy Office	As above	Deaf White British
13	Andrea	25	Jan	C Advocacy Office	As above	White British
14	Annette	22	Jan	C Advocacy Office	As above	White British
15	Harriet	37	Jan	C Advocacy Office	As above	High support needs White British
16	Shirley	26	Jan	C Advocacy Office	As above	White British
17	Julia	46	Advocacy worker	C Advocacy Office	As above	White British
18	Lucy	24	Jan	Skype	Skype interview supported by worker	White British
19	Pauline	61	Jan	OU office	One-to-one	Self-nominated White British

A flexible and evolving research method

The heterogeneity of recruitment routes determined that research methods were also flexible. The research team adhered to four principles in deciding the research method:

- One face-to-face interview⁵ with one or two members of the research team⁶
- Audio recorded, with recordings deleted after transcription⁷
- Including an advocate or other person(s) to support if requested by the interviewee or those close in their circle of support
- Location decided by preference of interviewee.

These broad principles allowed the team to flex its approach according to circumstance.

Pilot

The approach was piloted with Pauline, who, alone among the interviewees, personally contacted the research team to request an interview. She was the first person to be interviewed. Given her high level of literacy (contact made by email) and verbal fluency when arrangements to meet were made by phone, she seemed ideal to pilot the approach.

The interviewer used the easy-read project information leaflet (appendix 2) to inform Pauline about the project (emailed in advance), and to structure the interview.

⁵ On reflection it would have been advantageous to conduct a series of interviews with each woman. In the event, several interviews had two stages, a preparatory stage of some kind, followed by the interview.

⁶ Lou and Rohss worked as co-researchers.

⁷ Video recording was considered, particularly for women with little or no speech, but rejected because of issues of confidentiality.

The interview was fluent. However, despite Pauline's verbal fluency, it pointed to:

- The challenge of finding suitable language to use
- Difficulties in remembering sequences and describing details of contraception.

These issues were addressed in the project.

Easy-read PowerPoint questionnaire

The results of the pilot prompted reflection on the part of the research team, particularly as we were aware that we could not always rely on Pauline's level of literacy. Hence a PowerPoint was developed, in an easy-read format, with questions and suitable illustrations (see appendix 1). This provided the structure for all future interviews. It had several advantages:

- carefully chosen words likely to be understood by women with learning disabilities
- a consistent approach for the different members of a geographically dispersed team
- to inform Zamma Board members
- to provide advance notice of the questions, and, in some cases, enable supporters to work with the woman to prepare for the interview
- to use by other interviewers who, for logistical reasons, were called upon to conduct interviews
- suitable to prompt group discussion, as used with the C Advocacy Group.

There is the possible disadvantage that such a format deters women from wider ranging discussion as might be achieved in a more open-ended research approach. Nevertheless, we would recommend a questionnaire format for any future research of this type.

A range of interview types

Despite the consistency provided by the PowerPoint questionnaire, interviews came in all shapes and sizes, as the table below shows.

Types of interview format

Interviewee	Interviewer	Interview Format	Reasons for this format
Anne and Louise	Sue	2 women together, Informal café style with refreshments	All Zamma interviews attended by support worker and 2 senior managers. Anne and Louise had asked to be interviewed together
Patricia	Rohhss	1 interviewer, one respondent	One co-researcher conducted this interview
Susan	Rohhss	1 interviewer, one respondent	One co-researcher conducted this interview
Mary, Eileen and Alan	Rohhss & Lou	2 interviewers interviewed a family	Co-researchers conducted this interview. Mary does not use words, her parents were there to respond

Deborah	Rohhss & Lou	2 interviewers, one respondent	Co-researchers conducted this interview
Patsy	Advocacy worker	Group, individual interviews, followed by group	Research conducted at specially convened meeting of the female members of this advocacy group. Group discussion was the norm for them
Monica	Advocacy Director	As above	As above
Andrea	Jan	As above	As above
Annette	Jan	As above	As above
Harriet	Jan	As above	As above. When communication became difficult, an advocacy worker well known to Harriet was asked to join the interview
Shirley	Jan	As above	As above
Julia	Advocacy Director	As above	Advocacy Director conducted 3 interviews due to time constraints
Lucy	Jan	Skype interview supported by worker	Lucy unable to attend group meeting previous week. Advocacy worker to support her first use of Skype, also prompted during interview
Xanthe	Sue	One-to-one plus key worker, 2 senior managers, Informal conversational style	Key worker had worked through questions in advance with Xanthe, did not contribute to interview. One Zamma manager supported Xanthe to complete consent form at end of interview
Chloe	Advocacy worker	Advocate interview	Advocacy worker conducted interview on behalf of researcher as date changed at late stage. Researcher prepared advocate by talking through the questions and prompts in advance
Yvonne	Sue	One-to-one informal interview with refreshments.	To support conversational-style interview
Pauline	Jan	One-to-one	-
Freda	Sue	One-to-one	Unit manager and 2 senior Zamma managers. Informal interview with refreshments.

This range of formats was driven by the following factors:

- the request of the interviewee - Anne and Louise asked to be interviewed together
- to aid communication - Harriet went in search of assistance in getting her message across to the interviewer
- to enable a woman with no speech to contribute - Eileen and Alan, her parents, spoke for Mary
- to meet organisational requirements - Zamma recruited interviewees
- for logistical reasons - 3 interviews organised by C Advocacy Group, support to Skype interview for a woman unable to attend due to poor health

- preparation with a third party in advance: advance preparation was a feature of the Zamma interviews and those with C Advocacy. Zamma interviewees worked with staff known to them to prepare and where necessary research answers to the questionnaire. C Advocacy did some preparatory work with women who volunteered to be interviewed, and set up a group session preceding the interviews for the researcher to meet the women. Rohhss and Lou met three of the women they interviewed for a coffee prior to the recorded interview
- Provide emotional support for women on a subject which may trigger traumatic memories:
-all
- Cafe style layout of room with refreshments - all Zamma interviews used this style
- To explore the impact of a co-research model.

Rohhss and Lou worked together and did some interviews as co-researchers, as the project was committed to including a disabled researcher with knowledge of the topic. Rohhss notes that working together adds to the logistical challenges of any research project:

Working together

We tried to get dates and things together and that was difficult - for the women because they are busy - for me because I was juggling other work and for Lou because she had a lot going on around embedding her support at the house and all the new experiences from moving. If there had been more time we could maybe both have been at all the interviews.

Scaffolding the interview

There is a balance to be struck between allowing a woman to speak privately and in confidence with a researcher, and supporting women, for whom this might be the first time they have been interviewed for research, or spoken about contraception and sexual relationships. The research incorporated a range of scaffolding arrangements.

The pilot indicated that there might be value, in some cases, in drawing supporters into the research process. Although we remained fully committed to enabling women to speak for themselves, the pilot showed there were gaps in Pauline's knowledge of the type of contraception she had used, and why she used it. If we were to obtain important details, a third party might be able to assist. The team had neither the resources, nor the ethical approval, to access medical notes, but believed that supporters might have access to knowledge which the woman lacked.

A research finding was that more detail was disclosed in interviews where a trusted supporter had been involved. Furthermore, when they had been involved, supporters were in a position to provide both emotional and practical support, for example to encourage women to follow up with GPs when it emerged that contraception was in some respects unsatisfactory.

There were indications that more information might have been forthcoming in a series of interviews, to build up trust. Patricia mentioned that there were matters she was not comfortable to go into at the time but maybe would in the future, hinting at a more sensitive story. Deborah mentioned behaviour which might be interpreted as grooming, but only at the end of the interview, after the tape had been switched off.

The following vignettes illustrate some of the advantages, and disadvantages, of supporter involvement:

The advantages and disadvantages of supporter involvement

Meeting in advance of interviews

A meeting of the 12 women who had asked to be present was organised by C Advocacy to precede the interviews. All women had been informed about the research, and signed consent forms in advance. At the group meeting the researcher showed the questions on PowerPoint. A lively discussion ensued at which individuals explained what they understood about contraception. Some women began to talk about their individual experiences. The researcher cautioned against discussing matters which women might want to keep private. Nevertheless, some individuals did disclose information about their contraception in the group.

The women reconvened after lunch, to recap the findings from the day. The purpose was primarily to inform the advocacy workers of work they might want to pick up in future, with or on behalf of the women, for example, giving information about different types of contraception.

Harriet

Harriet was a member of the group from C Advocacy. She had been a vocal contributor to the group meeting which preceded her interview. During the interview it became clear that although she appeared to know about 'the pill', and said she had been taking not only the pill but also a contraceptive implant, she was taking a number of 'pills' and it was possible she was confused as to which was THE PILL. The researcher discussed this for some time with her. Harriet then suggested going in search of an Advocacy worker who knew her well. We did so, and the interview continued with the worker seeking to prompt Harriet. Despite this, it remains unclear whether Harriet did actually meet the criteria of taking contraception.

Lucy

Lucy was interviewed on Skype as she had been ill on the day the researcher visited. This was Lucy's first experience of Skype. She was accompanied by an advocacy worker, primarily to support her in using Skype. The advocacy worker later reported that she had supported Lucy to prepare for a visit to her GP to address issues which Lucy had raised in the interview. This is an instance where video data might have been of value.

Zamma Interviews

Each interview was supported by the organisation who ensured that support staff and managers were present as requested by the women. The organisation also tried to make sure the women were comfortable by providing refreshments and paying careful attention to the creation of relaxed, private settings. The same member of the senior management team made themselves available to support all interviews. This was reassuring for the women, direct support staff and managers alike. All women fed back that they had liked the interviews and are interested in the results of the study. None of the interviews were interrupted. All Zamma staff honoured the occasion by turning 'phones to silent and remaining in the background, allowing women to speak but being on hand to provide information as women required.

Mary, Eileen and Alan

Mary, Eileen and Alan were interviewed together because Mary has no speech. The researchers, Lou and Rohss, reported that Mary had appeared to be following the discussion. It was impossible to gauge the extent to which the views expressed were Mary's as opposed to those of her parents. This is an instance where video data might have been of value.

Feedback to participants and follow-up

The team is committed to feeding back to women who took part in an easy-read report. This has yet to be done as of necessity it follows this report. The easy-read summaries included in this report will be the basis for this feedback.

There will be dialogue with Zamma's management and with staff at C Advocacy about the findings, so that their strategies can be informed.

It is gratifying to note that in some cases action has already been taken to address issues which arose during the interview. Lucy, for example, asked the researcher to sum up what she had said in writing, and she was then supported by C Advocacy to take this in the form of a letter to her GP. The GP changed her contraception.

Responding to safeguarding issues and disclosures

Members of the research team took follow-up action with supporters to ensure that any information reported during interviews had been previously followed up in accordance with local and national safeguarding procedures and the law. Where abuse was disclosed from several decades earlier the individual, and with her consent her partner, was made aware of their right to seek legal redress or compensation if they chose to do so.

Some final reflections...

I must say this has been an eye opener for me being involved in this project and I feel privileged to have been part of it and to listen to the amazing although at times disturbing stories we encountered.

Zamma Senior Manager

How we did the research

	<p>We advertised for women to tell us about using contraceptives.</p> <p>It was not easy to find women who wanted to speak to us.</p> <p>We asked organisations to help us find women.</p>
	<p>Some women needed support to take part.</p> <p>Staff and advocacy groups provided support.</p>
	<p>We made easy-read information so everyone knew what to expect.</p>
	<p>We interviewed 19 women.</p> <p>We recorded their stories.</p>
	<p>We used these stories to write this report.</p>

Findings

(what we have found out about contraceptive choices)

Introduction

This section provides an overview of the main findings from the research project. We have organised this section to address the key research questions focusing on (1) the knowledge and understanding that women have about contraception; (2) the reasons why women say they use contraception; (3) how women talk about making contraceptive decisions; and, (4) how women describe they have been supported in making reproductive choices.

1. Knowledge and understanding about contraception

As part of the research process we ensured that research participants understood what was meant by contraception, the different types of contraception available and what contraception could be used for (also see our discussion of 'Research methods' in this report and appendices). By doing this we felt that we could achieve a shared understanding about the subject of the research. However, whilst levels of knowledge varied, it was clear that in some instances there was little knowledge and understanding about what contraception was and why it would be used. Sometimes the interview situation was used to tell women about contraception.

Interviewer: Contraception – do you know what it means?
Shirley: Your health? No, not much.
Harriett: Yes, I do something to do with wains⁸, not to get the wains, tablets, no wains.
Annette: I don't know much.
Interviewer: We can spend some of today explaining to those of you who don't know, and finding out from people who do.
Andrea: Yes, I know.

[Shirley, age 26, White British]

[Harriett, age 27, has high support needs, White British]

[Andrea, age 25, White British]

Our findings show that knowledge and understanding about contraception varied hugely. Some women felt very well informed about their contraceptive choices whereas other women were less knowledgeable or seemed to be uncertain.

Sex and pleasure

The findings suggest that for some women, contraception meant reproductive freedom; freedom from unintended pregnancy, unwanted children and painful periods as well as the freedom to enjoy sex. Women were asked specifically about what was good about using contraception.

Chloe: Can enjoy sex without having a baby. I don't get periods... It's nice to share about sex, it's natural. Sex is a funny thing. We smack each other's bums.

[age 43, has high support needs, White British]

⁸ Babies or children

Julia: *[I] Enjoy sex and periods don't hurt as much.*
[age 46, White British]

Interviewer: *So have there been good things about using contraception?*
Anne: *Yeah*
Interviewer: *What sort of things?*
Anne: *Well I don't need to worry.*
Interviewer: *About getting pregnant you mean?*
Anne: *Yes no worry.*
[age 40, Black British]

Interviewer: *Do you remember good things about being on the pill?*
Patsy: *Periods did not hurt so much.*
[age 51, White British]

Of course not all women believed that contraception was a good thing. Some were unsure about whether using contraception was a positive experience or not.

Interviewer: *What do you think are the good or bad things about using contraception, being on the pill?*
Patricia: *I don't know.*
[age 54, White British]

Other women were quite clear that there was nothing positive to be gained at all. In these instances women had often been prescribed contraception to alleviate symptoms and symptoms had either worsened or not improved. For example:

Yvonne: *... my periods were more painful too. Horrible.*
Interviewer: *Has there been anything good about using contraception?*
Yvonne: *Nothing at all.*
[age 56, has high support needs, White British]

Safe sex and being 'sensible'

The women interviewed also showed some understanding of how contraception could protect against sexually transmitted infections (STIs). Some women talked about or used the term 'safe sex'.

Interviewer: *What sort of contraception do you use now or have you used in the past?*
Chloe: *I have used the Pill, injection, implant - now - and condoms - 'safe sex'... We both had a HIV test at the clinic and a swab - it burnt T's penis- to check for gonorrhoea, chlamydia, AIDS... Safe sex is good, I don't get diseases.'*
[age 43, has high support needs, White British]

In general though most women were not as informed and there was evidence of some confusion.

Interviewer1: *Other things can happen if you don't use contraception. Who knows what they are?*

Shirley: STIs, AIDs, all sorts of things.
Interviewer 2: Pill won't protect from that
Shirley: No
Interviewer 1: What will protect you?
Shirley: Well, the bar, implant.
Interviewer 2: No, that won't either. What do you need to wear?
Shirley: Condoms every time, every time

[age 26, White British]

Other women talked about being 'sensible' and how taking action on contraception was the correct thing to do.

Yvonne: A few times we did it but we were sensible and he didn't put his you know inside of me so it was safe.

[age 56, has high support needs, White British]

Xanthe: ...if you are in a relationship, you see a specialist, get sensible contraception advice and also talk to a specialist about the right contraception with your doctor so your doctor knows your health, your previous history and what you are allergic to and everything like that. You have to put these things in place before you think of having a sexual relationship with anyone.

[age 28, White British]

Xanthe also recognised that contraception was not always reliable although this level of knowledge and understanding was atypical:

Xanthe: ...you can't always rely on it but it's a good thing to have as a stand by if you don't want to have a baby. But in some ways they don't always work especially the condoms they can split or leak sometimes. I know from my split one on the penis at school. And I do know that sometimes you take contraception and it doesn't work and you have a baby. You hear about all these young mothers you have had babies at 14, kids who are just teenagers themselves.

[age 28, White British]

Ideas about marriage, children and contraception

Many of the women interviewed expressed very traditional views about either not having sex before marriage (and therefore not needing contraception) or the importance of being in a stable relationship before thinking about having children.

Pauline: Unless you are in a stable relationship you should not have children.

[age 61, White British]

Lucy: I have a boyfriend but I haven't got started yet. You are supposed to wait until you are married.

[age 24, White British]

What is meant by 'contraception'?

Our research findings also suggest that using the term 'contraception' can be misleading or misunderstood. For example, some of the people who supported us in carrying out the research only thought about contraception in relation to sexually active women (for example, in order to prevent pregnancy). Women who may have been using contraception for other purposes (for example, to control painful menstruation) were seen as taking 'medication', rather than being on contraception. One of the research participants also describes something very similar:

- Interviewer: So you think the contraception tablets you are taking at the moment are more to help with managing period pains than to stop you having a baby?*
- Xanthe: Well no I'm not having a baby. No [laughs]. Because I don't take contraception unless I'm in a relationship. I don't see the point. I don't see the point in taking contraception if I'm not in a relationship. So it's not contraception.*

[age 28, White British]

2. The reasons why women use contraception

Participants in the study told us why they use contraception and explanations were varied. In some instances women made active and informed choices about contraception that enabled them to control their reproductive futures. In other cases women had used contraception because they felt they had to, or had been coerced; consequently they also had little say in the type of contraception they used. Some of the women also told us they used contraception as medication to regulate menstruation or alleviate menstrual pain.

Controlling pregnancy and reproduction

When asked about why they were using contraception, some women were quite clear that they only used contraception when they were having sex and stopped contraception when they were not.

- Interviewer: Why did you start to use it?*
- Shirley: Having sex.*

[age 26, White British]

- Interviewer: So at school did anyone suggest you ever went on contraception?*
- Yvonne: No no that was only if you had a boyfriend.*

[age 56, has high support needs, White British]

The women interviewed also said that they used contraception to prevent an unwanted pregnancy, either because they did not want children or felt it was too late to have any children.

- Julia: My decision, I did not want children. Teachers said it was my decision.*

[age 46, White British]

- Freda: I don't feel I'm ready to be a mother yet. Not ready to have a baby yet.*

[age 36, Black British]

Interviewer: Why are you using contraception now?
Susan: Because a) I don't really want to have kids. And b) I'm too old.
Interviewer: You're too old?
Susan: I'm too old now.

[age 49, White British]

One participant said she used contraception because if she became pregnant and had a baby she feared the child would be taken away from her again.

Andrea: I never want children would be too hard for me and social worker would take them away... My babies were taken away.

[age 25, White British]

A lack of reproductive freedom

Whilst some women are able to exercise reproductive choice this was not the case for every person interviewed for this project. It is interesting to note that Chloe and Yvonne, who both have high support needs, were either forced or coerced into having the contraceptive implant when they had lived in a care home. Both women describe having had no agency and fearing punishment; earlier life experiences that had not been forgotten. Chloe was forced to have an implant, although it is not clear from her account why this happened to her:

Interviewer: Who decided which type of contraception to use?
Chloe: 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.

[age 43, White British]

Yvonne also recalls an early unpleasant experience of contraception where she was made to take the contraceptive pill. She had not wanted to take the pill but had stopped because she was not having sex and did not feel that she needed to be on any form of contraception:

Yvonne: The manager took me to the doctor and asked for me to go on the tablets...
Interviewer: Why did they tell you to do that ? Do you remember?
Yvonne: Because they thought I was having sex every day and I said to them I am not having sex, but they didn't believe me.
Interviewer: And so you took it?
Yvonne: Had to, didn't I? I had no choice. They were giving it to me every day.

Then, Yvonne told us that she had been so 'fed up' that she had 'refused' to take the pill. She describes what happened next when she was tricked and forced into having an implant. This account relates to an incident in the mid-late 1970s:

Yvonne: They said [voice shaky], they said 'dress up I'm taking you out to dinner', 'I'm taking you somewhere really nice' ... [I] thought oh lovely so they took me in the car and when I got in they put a blindfold on me... And I said 'where am I?' and they said I'm not telling you... I was thinking I could hear cars but I couldn't see because they blindfolded me.

*They got me out and took me into this place and I could hear nurses and everything. I thought 'I'm not out to dinner am I?' Took me into a kind of operating theatre and they stuck this implant straight in my arm.
...they just strapped me down on the bed. I still had the blindfold on me [shouting sounding very upset]. They still had the blindfold on. Whilst they was doing it. It hurt so much I felt the pain and went 'aaah'. The pain really hurt in my arm and they ripped half of my skin off [points to place on arm]. That there you can't see it now because it's all gone but the skin was all ripped.*

Interviewer: Yvonne, I'm so sorry. That's terrible. I had no idea that had happened to you.

Yvonne: I was crying my eyes out and the staff said 'I don't fucking care'. They swore at me. They called me a B , they called me bastard. And that's what happened....

Interviewer: And then did they do that again because they had to renew the implant?

Yvonne: I had to do it. Otherwise they would have punished me. I had to keep going back. Until I left.

[age 56, has high support needs, White British]

Managing 'risky' behaviour and a lack of trust

Yvonne's account is one of the most extreme we encountered but several women also reported being on contraception because they were not trusted or believed. Sometimes women's behaviour was seen as risky or promiscuous.

Pauline: My parents had to do something (about contraception). They couldn't keep an eye on me 24 hours a day. They could not trust me... On my mum and dad's mind was the possibility of me getting raped. I was bringing men to my flat at 1 in the morning and asking mum and dad to sort it out. I did not have any choice about contraception. Did not know what was available. But your parents can't keep an eye on you 24 hours a day. They didn't want me to live on my own. I don't think I really understood.

[age 61, White British]

Patricia told us that she had visited her doctor because of her periods but suspects that others were also worried about her sexual behaviour:

Interviewer: Can you tell me if you have ever used any contraception?

Patricia: When I was in my twenties I went to the doctor because I had heavy periods, me Mam took me to the doctor. He said we had better put you on the pill.

Interviewer: How did you feel about that?

Patricia: I was happy because it sorted my periods out. I took it every morning. I had lighter periods. But sometimes people were bothered about my behaviour it was to do with that... I got into trouble at college. A boy touched me and so I don't go with boys anymore. But I liked it and I had feelings for him. He is going with another girl now.

[age 54, White British]

On a similar theme, in the interview with Mary's parents they describe how doctors wanted to put Mary on contraception 'for her periods' at the age of 15. Her parents recount their feelings of shock and disbelief.

Mary's mother: ...what I found when she was 15, was that they tried to put her on contraception when she wasn't in a relationship and didn't need it.... I was quite taken aback and a bit shocked at the time.

...almost as soon as her periods started that the paediatrician wanted to put her on the pill. And I sort of said, 'well why do you want to put her on the pill?', and it was like, 'well, periods are messy'. And I was like, 'well, Mary is doubly incontinent and how is cleaning somebody with a period any different from cleaning somebody if they have had a bowel movement or a wee, it's ...'

Interviewer 1: Well, to be honest, periods can be messy for anybody can't they?

Later they also talk about other reasons why contraception may have been suggested for Mary even at a time when she was not sexually active; these reasons include the risk of rape, the management of sexual behaviour, and convenience for others.

Mary's mother: ... and then he said, 'And there might be boys', and I said, 'Well what do you mean by that?' and it was sort of 'well, ...well it was like, basically she might have sex kind of thing ...and there might be a baby'. And I said, 'surely the time to discuss contraception is when he is actually in a relationship with somebody...not before?'

...well basically, I didn't give consent another thing was he wanted to put her on the contraception where they put rods under the skin.

...I can't understand why you would put somebody on chemicals that are quite risky for the sake of what? In case they have sex? In case they get raped? What? What? Surely if they are in that dangerous situation - that needs to be thought through and not just put her on the pill.... what about the boys?

Interviewer 1: Exactly.

Mary's mother: Do we sterilise them?

Interviewer 2: Yes there are huge gender inequalities there...

Mary's father: I think that there's um....there's a presumption that what parents are actually looking for - um, particularly in children with learning disabilities - is convenience and safety, to manage painful periods or to regulate periods.

...It's a model of protection that I think stems from a realisation that in a lot of care settings traditionally people were very vulnerable to all types of sexual assault and predation and so if you bang them on contraception permanently then you may not be able to protect them from being assaulted but you can protect them from getting pregnant as a result of that. And, I don't know, I do think that's where that notion has its roots basically.

[Mary, age 19, White British]

Managing menstruation

Although many women use contraception to prevent pregnancy and some have had little or no reproductive freedom, several women said that they use contraception to manage the symptoms of menstruation including managing heavy periods, irregular periods or the management of menstrual pain.

Monica: *On pill.*
Interviewer: *Why?*
Monica: *Periods.*

[age 26, White British]

Andrea: *... my periods were very, very heavy. Got implant in my arm.*
Harriet: *I got periods as well.*
Shirley: *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.*

[Andrea, age 25, White British]

[Harriet, age 37, has high support needs, White British]

[Shirley, age 26, White British]

3. Making decisions about contraception

There is a continuum of reproductive decision-making with some women feeling that they are responsible for making independent and informed contraceptive choices, through to experiences of coercion and force where women have had no choice whether to take contraception or not, and no choice in the type of contraception they are on (these experiences were discussed in the previous section). It is worth noting here of course that the research participants are aged between 20 and 61 years and so some of the experiences recounted are historical rather than contemporary. Somewhere in the middle of this continuum, many women are making decisions but those decisions are not necessarily fully informed.

Reproductive control and gender relations

As we recruited women to the research and began interviewing, there were some disclosures of sexual abuse (this is discussed in the 'Research methods' section) including allegations of rape, grooming and partner violence. However, it was also really interesting to note that a few women were very cognisant of their reproductive rights and felt powerful when negotiating safe sex and contraceptive use with male partners.

Interviewer: *Do you have a relationship?*
Andrea: *I have somebody at the minute. I always tell him to use condoms all the time. I always say use condom or we are not having sex. He says I don't like the lycra and I say I'll just walk out.*

[age 25, White British]

Xanthe: *So he took me to his flat and he cooked me dinner then we started doing the thing. I said I hope you've got a good like contraception around you because I'm not having a baby with you now not just after I met you. And he goes fine then I'll need a condom then...*

[age 28, White British]

Of course not all of the women interviewed were currently in a relationship and at least one woman was internet dating only.

Taking the initiative for contraception

Women possess varying degrees of knowledge and understanding about contraceptive use and this makes it a difficult topic to talk about. It is also a topic that can be considered private and taboo. In spite of this, a number of participants told us that they had taken the initiative to find out about contraception. They also told us that the decision to use contraception was made by them.

Julia: I wasn't ready to have a baby. I went to the doctor to get more information

Interviewer: Did anyone talk to you about it? Nurse, social worker?

Julia: No

Interviewer: Just took off by yourself?

Julia: Yes

[age 46, White British]

Xanthe: I have taken the initiative to help myself. It's like if I didn't I wouldn't know all this.

[age 28, White British]

Only one woman interviewed had been sterilised and she described this as her choice:

Interviewer: Patsy, you had an operation, is that right?

Patsy: Had sterilisation operation after Johnny (second child) was born. Before that did not use any contraception. I did take the pill after Johnny was born. My decision to do that. Me and my husband went to the doctor.

[age 51, White British]

In addition to sterilisation, women reported using a wide range of contraceptive methods including the contraceptive pill, the mini-pill, contraceptive patches, implants, injections and condoms, as well as non-penetrative sex. None of the women interviewed used an IUS or IUD; although these had been discussed women were often told they were not suitable. Some women had used only one method of contraception whereas others had used several over their reproductive life-span.

Chloe, who had been forced to have an implant at an earlier time, describes how she is now able to make her own decisions:

Chloe: I have been using contraception since I was 16... I had fruit flavour condoms and used to blow up balloons. Then I used the Pill. I didn't like the needles for the injections (2 years) then I was forced to have the implant. Now I make my own decisions.

[age 43, has high support needs, White British]

Taking contraceptive decisions together

For many of the participants, decisions about contraception are made more collaboratively. Sometimes this means contraception is first suggested by someone else. It can also mean that decisions are taken through discussion with others even if the final decision is being made by the woman herself.

Interviewer: So when you decided to go on the implant whose decision was that?
Freda: It was [the key workers] [talking about events in last year]
Interviewer: Did they include you in talking about that?
Freda: [nods] I wanted to be there myself.
Interviewer: Was it helpful? Talking with them?
Freda: I thought it was right because I not ready for a baby.
Interviewer: So you thought it was the right thing to do?
Freda: For me for myself and the staff and my friends, my family, myself as well. It was what I wanted. Myself as well.

[age 36, Black British]

Although it was difficult to remember how the decision was made, with the unit manager's help, Louise also discusses her contraceptive decisions:

Interviewer: Do you know why you started to use contraception?
Louise: Can't remember. I don't know. My manager [name] will help me because I don't remember [sounds a bit agitated].
Interviewer: It's ok don't worry. These things are sometimes hard to remember.
Louise: I know I know. [name] my key worker. She can tell you because it's hard for me to remember. [name] you tell her...
Manager: There's was concerns...do you remember to make sure you don't get into the family way?
Louise: Yeah
Manager: And it was discussed between you and your social worker.
Louise: And mum?
Manager: And your mum and the manager who used to manage the house. Together you came up with a decision in your review that it would be the best way to go.
Interviewer: So that's very clear. Thank you.
Louise: Yes.

[age 32, Philippino]

Yvonne, who had been forced to use contraception in another setting because she was not trusted or believed told us about a more recent experience where she felt more in control of her contraceptive choices. She told us that it was important to have 'people who stick up for you and help':

Yvonne: She [the manager] took me to the doctors, she went with me and got me taken off the pill and the implant.
Interviewer: And you didn't use the pill again after that?
Yvonne: No because they trusted me. They talked to me.
Interviewer: So after that you have made your own decisions? You and Brian have decided together what is best for you?
Yvonne: Yes, yes.

[age 56, has high support needs, White British]

Mary's parents also talk about wanting to take contraceptive decisions collaboratively should Mary embark on a sexual relationship with her boyfriend:

Mary's mother: If Mary consented to a sexual relationship, I would struggle with that. However we have discussed it with Mary and her staff team, you know what I mean? Should that event arise... and yeah, that's all I wanted to say really.

Mary's father: ... so it's about finding out what she [Mary] actually wants.

[Mary, age 19, has high support needs, White British]

Passive acquiescence

The research suggests that there is some evidence of passive acquiescence; that is, when women allow others to make decisions for them. This is distinct from the examples given above where women feel that the final decision - however it is made - is made by them. More passively, sometimes a woman may believe that someone else knows best - usually a health professional - and in others the woman exercises very little agency and cannot make an informed decision because she has no access to information or further advice.

Some of the women did not seem to make their own contraceptive choices. When asked about this they said that the doctor had made the decision for them.

Interviewer: Did you get information?

Harriet: Doctor decided

[age 37, has high support needs, White British]

Monica: On pill

Interviewer: Why?

Monica: Periods

Interviewer: Who decided? Show me

Monica: (points to nurse on questionnaire)

Interviewer: Who decided you needed it?

Monica: (points to support worker image)

[age 26, White British]

Other women reported that they allowed the doctor to decide but that they did not have enough information to make a decision; there is a general assumption that 'doctor knows best' and this is rarely questioned.

Andrea: Grannie told me about it. We went to the doctors and doctor said we'll give her an implant because it's better than periods. I have the pill as well, use it as well to stop the bleeding

Interviewer: Doctor decided?

Andrea: Mmm.

Interviewer: And you agreed?

Andrea: Yes, not enough information

[age 25, White British]

Interviewer: Why did you choose the implant?

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

Interviewer: Would you have liked more information?

Shirley: Uh-huh.

[age 26, White British]

In the final section below, the issue of information, advice and support is discussed and women talk about what they need to ensure that they can make informed choices.

4. How women are supported to make contraceptive choices

The interviews suggest that many women are being really well supported to make contraceptive choices. Some women feel strong and capable in how they access services and find information drawing on a range of sources such as support from family, health professionals and even the internet. Other women do not feel supported, either because they feel coerced, because they lack knowledge or information, or because choices are being made for them with little consultation or discussion. In some instances contraception is being regularly reviewed to ensure that it continues to be safe and effective. Some women also told us that their contraception was not reviewed or that they could not remember. The findings suggest that access to good quality information that women can understand is essential to ensuring that women can make their own reproductive choices.

Social support

Women valued good support that placed their needs at the centre of decision-making. In many instances women were able to make decisions either wholly or partly independently. A very wide range of family members were named as providing support including grandparents, parents, siblings, uncles and aunts, and cousins. Others were also mentioned including support workers and professional staff.

Interviewer: You have an implant. When?

Andrea: Must have been 20 or something... Grannie told me about it.

[age 25, White British]

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

[Harriet, age 27, has high support needs, White British]

Xanthe: I had to find out from mum, the support worker at school in the classroom, my sister... that's it really.

Interviewer: And did your mum and sister give you quite a lot of information? Were your family quite helpful about contraception advice?

Xanthe: Mostly my dad did. He gave me the information [laughs] so there you go but then he said if you have any questions ask your mother!

[age 28, White British]

A few of the women in the study talked about needing support in order to take their contraception effectively. In several cases, women who were taking the pill sometimes changed to another form of contraception because they could not remember to take it.

Freda: I'm not good and I miss one pill. I remember. Got it in my mind. And I had a key worker to keep me in touch with that. Calendar.

[age 36, Black British]

Susan: I had a chat to my doctor, then I had a chat with the nurse. Then I decided afterwards which one to go for. I decided to take the

pill first. But then I kept on forgetting it. And then the danger of me becoming pregnant at at my age, it was daunting and scary....so I went over then to the Depo.

[age 49, White British]

Susan said that she was also supported by her friends although this was the exception.

Interviewer: You've talked about the doctor and the nurse. Have you talked to any other people about going on contraception?

Susan: Well I talked to one of my friends. I did talk to friends. They told me what they were all on. And then I decided on the injection.

[age 49, White British]

Information, advice and education

As highlighted in the section above, women indicate that they have received or sought advice from a range of individuals including family and friends, carers, support workers and health and social care professionals. Some women also recall their experiences of sex education although did not think it had been that useful.

Interviewer: Did you have any sex education at school?

Patricia: Yes, I went to school, we had some and everyone was laughing.

[age 54, White British]

Interviewer: You'd had some sex education classes at school?

Xanthe: But we didn't learn actually. We had this sex woman come in and she had these rubber penises. We had to try to put these condoms on these plastic penises. And mine split. [we laugh] I went too far! The end of the penis came open you know. And then she said now try a banana.

Interviewer: Yes I remember the banana business from my school! A lot of people had problems with that [we laugh].

[age 28, White British]

Mary's parents also talk about her experience of sex education in a mainstream school:

Mary's mother: As I say, I had felt that in terms of Mary's sex education, she had a full sexual education because she had been at a mainstream school, she had quite a formal education about sex and babies and all that sort of thing, but she had also had an informal education from girls her own age. I saw her at school flirting with some boys, not flirting with others, and I felt she was well informed, you know...

[Mary, age 19, White British]

During the interviews women were asked specifically about any information they had received to help them make informed decisions about contraception. They were also asked whether the information was helpful and what else they might find useful in the future.

Some women did not receive particularly good information or could not remember specifically. Other women could recall receiving useful information, particularly leaflets.

Lucy: It started well but then went back... I did not get much information. No leaflets I would have liked more information.
[age 24, White British]

Interviewer: Did you get information about the Pill when you went on it?
Anne: An easy-read I think. I got information.
Interviewer: Oh right. That's good.
Louise: My doctor said about it.
Interviewer: Did you have clear information?
Louise: Not really I don't think so I can't remember.
Anne: I did. I have something with pictures.
 [Anne, age 40, Black British]
 [Louise, age 32, Philippino]

Other participants who may not have found information useful or received very little felt that easy-read information was necessary including information with pictures. Leaflets were a useful source of information.

Chloe: I would have liked more information about sex and about diseases. People with learning disabilities need more information – what sex is all about. For couple about different positions; I would like picture information about sex with big pictures and smiley faces.
[age 40, Black British]

Xanthe: When I look at a medical magazine or anything like that it is difficult for me to understand it. So much that I just discard it. So much information is not laid out in a way that I would understand. If I have it set out in a way that I understand with words that I understand. Some medical books well the writing but words medical words can't really change but I would find things easier to understand if...sort of like a big sort of when you have some people find it hard it hard to read unless it is in easy-read format... Although I'm quite good at reading some people can't even read but I like easy-read it easier to see what are the main bits. If you see the pictures you can still follow it.

Xanthe was the only participant who mentioned the internet as an important source of information but this is likely to become more important over time as increasing number of women become IT confident.

Xanthe: ... we went straight to our room and searched it! Went on the internet.
Interviewer: And is that how you've found out about things like parenting?
Xanthe: Yes a lot.
 [age 28, White British]

Planning and review of contraception

The findings suggest that there is some evidence of contraception being reviewed regularly and women being involved in contraceptive decision-making at those review points. Reviewing contraception is important because it can have serious long-term side effects for health. In the

short term it also means that the efficacy of the contraception can be checked and, if necessary, the method or type of contraceptive can be changed or stopped.

Two of the women interviewed together talk about having their contraception reviewed as part of a Health Action Plan:

- Manager:* Louise do you mind me saying that you had your pill changed yesterday?
- Louise:* No. Changed. Doctors yesterday. You tell [manager].
- Manager:* Louise came off the Microgynon. They, the doctor said that basically they are phasing a lot of that out as there have been some side effects and replacing it. And now she has been put on [something else].
- Interviewer:* Now that answers one of my later questions! [both smile] as it sounds like you get your contraception checked by the doctor?
- Manager:* Both of you have Health Action Plans, which means you go and have a yearly check up with the doctor. That's with the GP
- Louise:* Yes up here...
- Anne:* And I don't like the way they talk about personal things things that I don't want to go through.
- Manager:* Well you're not keen on the doctor are you [talking to Anne]
- Anne:* No no.
- Manager:* But you go along for your Health Action Plan?
- Anne:* Yeah, yeah.
- Interviewer:* That's very good you are getting it checked regularly - is that every 12 months the Health Action Plan?
- Anne:* Yes.

[Anne, age 40, Black British]

[Louise, age 32, Philippino]

Freda, who lives in the same supported living setting as Anne and Louise, also has her contraception reviewed in this way:

- Interviewer:* And since you've had the implants Freda have they been checked?
- Freda:* Yes.
- Interviewer:* Do they do that every year or every...?
- Manager:* It's usually when you have your medication review. The review is usually every 6 months or so as well as the health action plan. The Health Action Plan system-they go through that then too. Check it.
- Interviewer:* It seems you have good systems for checking.

[age 36, Black British]

There were many more instances where contraception does not seem to be reviewed on a regular basis even when there might be compelling reasons to do so. The findings also suggest that some women seemed unsure about whether their contraception was reviewed or not.

- Interviewer:* And did the school (boarding school) also check it?
- Yvonne:* No they never gave me a check or nothing.
- Interviewer:* Did they ever check your blood pressure or anything like that?
- Yvonne:* I don't remember that at all.

[age 56, has high support needs, White British]

Xanthe: ... Apparently according to the gynaecologist she was saying I got a premature menopause [laughs].

Interviewer: And are they going to do anything else about that? Any bone scans for example?

Xanthe: Oh I don't know.

Interviewer: The gynaecologist is monitoring this?

Xanthe: They said they, they said they will call you or send a letter if they need to see me again.

Interviewer: And when was this?

Xanthe: A while ago. Over a year. So that's that.

Interviewer: So when you were taking the patches do you remember if anyone like a doctor or nurse gave you a blood test or talked to you about the patches or pills?

Xanthe: No I can't remember anything like that. It was more are you using then? Are you taking them? That was the doctor's advice. I have never had a bone scan that I remember.

[age 28, White British]

Doing this research project has made it clear that talking about contraception can be really hard for women. Some women were quite clear about their preference for a female doctor. Even when women did not express a clear preference, the gender of the doctor or nurse was often mentioned in interviews indicating that this is something that should be taken into consideration when women with learning disabilities are seeking advice on contraception.

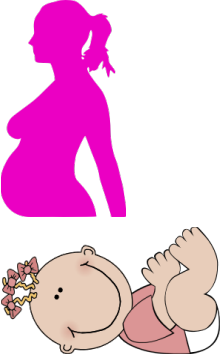




Lucy: I don't like speaking to men doctors. It helped a little bit but then went back to where it was before. My periods still hurt. At the moment I struggle with them because I have a very sore tummy. I still think basically my periods are still heavy. But I feel nervous talking to the doctor.

[age 24, White British]

Patricia: Some people could be nervous and want to see a lady doctor.

[age 54, White British]

What we found out about contraception

	<p>Some women know a lot about contraception and that it can be used for different reasons such as if you have sex and don't want to have a baby.</p> <p>Other women don't know very much about contraception.</p>
	<p>Women often choose whether they want to use contraception.</p> <p>They also make choices about what contraception to use, such as condoms, the pill or the implant.</p>
	<p>Some women have been forced to use contraception even if they didn't need to.</p>
	<p>Some women decide that they want to use contraception and find out about it.</p> <p>Some women use contraception because other people think it is best for them.</p>
	<p>Women can make good choices about contraception when they are well supported by friends, family, carers, doctors and others.</p> <p>Many women said they want more information and that it should be easy to read and have pictures.</p>

Summary of key findings

(a summary of what we have found out)

Key findings

Women's experiences of contraceptive decision-making vary hugely, as do levels of experience, knowledge and understanding. Some key messages emerge from the research project which takes into account this diversity of experience. These key messages are summarised as follows (and are also listed in the Executive summary):

- Knowledge and understanding of contraception vary and it is sometimes difficult to achieve a shared understanding of what contraception is.
- Contraceptive use is associated with sex, pregnancy and parenting and when women use contraception for other purposes it may not be recognised as such.
- Women report using contraception for a variety of reasons including the prevention of unwanted pregnancy and because they want to delay, or do not want to have, children. Some women use contraception to manage menstruation.
- Sometimes women are on contraception because they are not trusted or believed, or because they are thought to be 'at risk' of pregnancy and abuse.
- A few women make very independent choices about sex and contraception and others are supported to make contraceptive choices by family, friends, advocates and health and social care professionals.
- Some women do not receive suitable information or advice to make informed contraceptive choices and other people make decisions for them.
- Historically, some women have been forced to use contraception when it was not needed and these experiences have had a lasting effect on them.
- There is evidence that contraceptive use is sometimes effectively planned, managed and reviewed but in other instances this is not the case.
- Women appreciate staff who will listen carefully to concerns about contraception and relationships and support them to access the best contraception care.

Implications for policy and practice

Drawing on the research findings presented in this report we set out some implications for policy and practice that would go some way in supporting women with learning disabilities to make appropriate contraceptive choices (these are also included in the Executive summary).

- Improved access to sex education and information about contraception would help women with learning disabilities make decisions about sex, pregnancy and parenting.
- More easy-read information with pictures would be useful to help them make contraceptive choices.
- Sometimes women would prefer to speak to a female doctor or nurse and this should be respected.
- Closer monitoring and reviewing of contraception would help women manage their contraceptive use more effectively and may have longer term benefits to health.
- Specialist advice and support should be available to women with high support needs who are more vulnerable to coercion.

Implications for further research

We have set out to provide a detailed and honest, ‘warts and all’ account of the research process. Recruiting women to the project was one of the most challenging aspects of the research and we were creative in how we found research participants; without the proactive support of Zamma and C Advocacy, particularly that of senior staff who were committed to the project, our task would have been far more difficult. Given a range of demands, and the sensitivities of the project, the interview process was also iterative. This is to be expected when interviewing women with learning disabilities but women *and* service providers found it difficult to talk about contraception. The interviews varied in type and duration, although were all structured around a common set of questions; we believe there was value in this heterogeneity. We set out some implications for future research (these are also included in the Executive summary).

- Little is known about the contraceptive choices of women with high support needs; but next to nothing is known about women who fall under Mental Capacity Act legislation in the UK. Urgent research is needed to explore their experiences.
- An inclusive co-research model is valuable but it should be acknowledged that it takes more time to work in this way.
- Working with sympathetic organisations to recruit respondents is essential.
- An easy-read illustrated questionnaire, or similar, is a useful tool in guiding conversations and it is helpful when this is shared with women (and/or support workers) prior to interviews.
- Researchers should be open to different ways of supporting women before, during and after interviews.
- Interviews should enable women to express their views freely but it can also be useful when women are supported to participate.
- A series of interviews with each woman should be conducted and interviews should be informal and relaxed, paying attention to language, location and ambience.

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Appendices

(additional material that we used to support the project)

Appendix 1 - Examples of the easy-read PowerPoint presentation

Why did you start to use contraception?

I don't know

I was worried I would have a baby

Other people were worried I would have a baby

To manage my periods

To help with my mood

Another reason



What sort of contraception do you use now or have you used in the past?







- The Pill
- Injection
- Implant
- Coil
- Condom
- Cap






Appendix 2 - Easy-read project information

leaflet

Appendix
3 - Easy-
read
consent
form

<p>5 Open University ☎ (0)1908 (0) 1908 654 260</p> <p>✉ s.earle@open.ac.uk</p> <p>If you have any concerns or complaints about this research please contact:</p> <p>Professor Brigid Featherstone The Open University ✉ brigid.featherstone@open.ac.uk</p>		<p>for</p>	<p>4 We will not use your real name in our Report.</p> <p>You can change your mind at any time.</p>	<p>John Smith</p> 
<p>or</p> <p>Sue Ledger</p> <p>You can ask a friend, advocate or relative to come with you to support you.</p>	 	<p>ories f</p> <p>y stor</p>	<p>If you do, we will not use your words in our report or in anything else we publish.</p> <p>You can do this by phoning us, emailing us, or writing to us.</p> <p>Would you like to find out more?</p> <p>Please contact –</p> <p>Dr Sarah Earle</p>	 

<p>Anything else to say?</p>	
 <p>Name</p>	
 <p>Address</p>	
 <p>Signature</p>	<p>Date</p>

Please turn over and complete page 2 if the person named above needed support to make this decision.

<p>If I needed support to make these decisions This is who supported me:</p> <p>Name:</p> <p>Relationship:</p> <p>Signature:</p> <p>Date:</p> <p>This is how they supported me:</p>
--

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