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'I have the jab so I can't be blamed for getting pregnant': Contraception and women with learning disabilities[☆]

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SYNOPSIS

The aim of this research was to investigate whether, and to what extent, women with learning disabilities were enabled to exercise choice and control when it came to their use of contraception. Semi-structured in-depth interviews were conducted with 23 women with learning disabilities in the UK to explore these issues. Findings suggest that most women with learning disabilities did not make their own decisions and some of those who did, found their choices constrained by various factors, such as their young age, fears of losing their service, and previous traumatic experiences. The over-use of Depo-Provera is discussed, as are the common practices of giving contraception to women who are not sexually active and those whose fertility has declined naturally due to their age. The factors which lead to women's relative lack of autonomy are explored.

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Introduction

"Women with learning disabilities are women too" (Williams, 1992, p.149). An obvious statement of fact, yet all too often women with learning disabilities are still regarded as fundamentally different from other women. The marginalisation of women with learning disabilities from both feminist and disability right analyses has long been recognised (Rodgers, 2001), yet it has seldom been rectified:

"...the intersection of feminism and disability studies has been one of the least explored because of the dominance of disability as the primary category of analysis and the avoidance of feminist studies to include disability in their categories of difference. This process, whereby women with disabilities have fallen through the gaps of definition, theory, and consciousness, has manufactured a silence around them and their experiences" (Chenoweth, 1996, p.394).

However, some feminist researchers have attempted to fill this silence, by acknowledging the impact of gender power

relations on the lives of women with learning disabilities in areas such as identity (Burns, 1993), sexuality (McCarthy, 1999), employment (Noonan Walsh, 2000), menstruation (Rodgers, 2001) and parenting (Baum & Burns, 2007). The above are examples of non-disabled researchers, but increasingly women with learning disabilities themselves are being given a voice through the use of inclusive research practices (Walmsley & Johnson, 2003).

Contraception and women with learning disabilities

Reproductive health care for women with learning disabilities has a controversial and, until relatively recently, a wholly negative history. Historically, people with learning disabilities were considered to be either child-like and asexual or promiscuous and a sexual threat to others (Koegel & Whittemore, 1983). Because the reproductive capacity of women with learning disabilities was deemed to be a social threat, enforced sterilizations and institutionalisation with strict segregation of the sexes were strong features of twentieth century approaches (Kempton & Kahn, 1991). Thankfully such overtly eugenic practices have largely ceased (although where sterilization rates are researched, they still suggest very high rates e.g. 22% of women with learning disabilities in a recent Belgian study compared with only 7% of

[☆] Learning disabilities is a term widely used in the UK. In an international context, it is used interchangeably with intellectual, cognitive or developmental disabilities.

the general Belgian population (Servais, Leach, Jacques, & Roussaux, 2004 p. 429)). However, certain features of contraceptive practices revealed in this research project suggest that preventing pregnancies in women with learning disabilities still takes place at the expense of the woman's well-being and dignity (see below).

Although relatively little research has been conducted to directly examine patterns of contraception use amongst women with learning disabilities (Stinson, Christian, & Dotson, 2002), some studies have done this (e.g. Chamberlain, Rauh, Passer, McGrath, & Burket, 1984; Servais et al., 2002). Also information about women's use of contraception has come indirectly from studies looking at wider issues of sexuality (McCarthy, 1999). What the available evidence shows quite clearly is that the pattern of contraceptive use amongst women with learning disabilities does not match that of other women of child-bearing age. It has long been recognised that Depo-Provera is disproportionately used with women with learning disabilities (Welner, 1997). Historically there has been a disproportionately high use of IUDs in younger women with learning disabilities who have not had children (McCarthy, 1999), although this trend seems to have abated, as other long term contraceptives have become available. The use of barrier methods amongst this group of women is very uncommon, with Servais et al describing them as 'never advocated' (2002:110). The Pill is a commonly used method of contraception for women with learning disabilities (as it is for women in the general population). The literature notes that as well as prescribing the Pill to prevent unwanted pregnancies, it is also common to prescribe it to women with learning disabilities to manage menstrual problems (Carlson & Wilson, 1994) and, as this research also demonstrates, it is also given to women with learning disabilities who do not have menstrual problems and who are not sexually active (see also Keywood, Fovargue, & Flynn, 1999).

The gap between policy and practice

In 2001 the UK government published *Valuing People: A New Strategy for Learning disability for the 21st century* (Dept. of Health, 2001). It was underpinned by the four key principles of rights, independence, choice and inclusion. It explicitly stated that people with learning disabilities should be enabled a) to have more choice and control over their lives (p.44) and b) to access a health service designed around their individual needs (p.59). Previous government policy documents e.g. *Signposts for Success* (Dept. of Health, 1998), *Once a Day* (NHS Executive, 1999) had clearly stated the principle of full rights of equal access to health care provision for people with learning disabilities. The policy framework relating to healthcare specifically, and that of the wider disability rights arena, could not therefore be clearer in stating that people with learning disabilities have a right to receive good quality healthcare and equal treatment alongside other citizens. And yet, with depressing regularity, report after report suggests that in reality there are many difficulties, barriers and unsatisfactory experiences when people with learning disabilities attempt to have their health needs met (Disability Rights Commission, 2006; Mencap, 2007; The Michael Inquiry, 2008). Looking at healthcare provision for people with learning disabilities through an even wider lens, it is

possible to see that neither the UK disability discrimination legislation (see below for an example) nor the European Convention on Human Rights¹ is being adhered to.

Methods

The research took place in two counties in South East England. Semi-structured in-depth interviews were conducted with 23 women with learning disabilities. In-depth interviews were chosen, as a form of enquiry was needed which went directly to women with learning disabilities. Questionnaires would not have been suitable because of the literacy problems faced by most people with learning disabilities. The interviews were semi-structured, because both highly structured and unstructured interviews are unsuitable for many people with learning disabilities (for a full examination of interviewing with people with learning disabilities, see McCarthy, 1999).

A purposive sampling strategy was used to select women who had current or recent experience of using contraception, were living in community based settings and were able and willing to discuss their experiences.

All interviews were recorded and transcribed and a multi-staged narrative analysis was undertaken (Stevens, 1994). This method requires the researcher to first become very familiar with each individual transcript and a content analysis is then used to code the data. The data are then reorganised to allow for categorisation, examination of basic themes, shared experiences and diversity. After this initial analysis, transcripts are then re-read. This system of emergent coding allows for themes and sub-themes to be searched for until no more emerge (Stemler, 2001).

Ethical approval was gained from a university research ethics committee, as well as those of the relevant health authorities. Accessible briefing information and consent forms were developed for participants. Potential participants were first asked if they were interested in taking part by a known and trusted person e.g. community nurse. If they were interested, they were visited by the researcher who explained the project in detail and what they would be required to do. Even if they consented to participate there and then, they were still given time to consider and were visited again, usually one week later, to check if they had changed their mind or remained interested. Those who wished to proceed then signed consent forms and interviews began. All participants were later paid a small amount to thank them for their efforts.

A service user group was actively involved in the formative stages of the project. The importance of their contribution was to act as a point of reference for the researcher. For example, their views were sought about the intended questions for the interview schedule. It transpired that they had relatively few comments to make, but these did lead to some modest refinements and changes. Stalker (1998:16) has commented on how people with learning disabilities frequently find it difficult to 'advise' academic researchers, but often contribute to research projects by sharing their own experiences: 'Thus we [tap] into individuals' particular expertise rather than expecting them to possess a level of research awareness, which for a number of reasons, they may not.' This is an accurate description of what happened in this

research project. I found that the service user group was not especially 'research minded' (nor would most people in the general population be) and it was unrealistic to expect that they could advise on a research project in general terms. But they were very able and willing to share their own experiences and opinions, as a way of advising me what I should be exploring with research participants. I am aware that with greater levels of support and expertise than I was able to provide, it is, of course, possible for people with learning disabilities to make significant contributions to the whole research process (Walmsley & Johnson, 2003).

The participants

23 women were interviewed about their use of contraception. They were aged between 20 and 51. The oldest woman was no longer using contraception, but had done so until relatively recently.

19 women were White British, 2 were Black British (of African and West Indian origin). One was Mauritian and one southern European.

All the women had mild or moderate learning disabilities. This is a reflection of the fact that the participants needed to be able to talk about their views and experiences. The exclusion of people with more severe and profound learning disabilities is an inevitable consequence of this research method and as such, is one of the limitations of this study.

Of the 23 women, 12 lived independently or semi-independently (e.g. in supported living schemes), 8 lived in learning disability residential services and 3 lived with their parents.

Between the 23 women, there had been a total of 13 pregnancies, resulting in 9 children, 2 stillbirths and 2 abortions. Of the 9 children, 7 were taken into local authority care and 2 (young children) were living with their mothers.

The 23 women were all either current or recent users of contraception: 11 used the Depo-Provera injection; 7 were on the Pill; 3 used an IUD; 1 had an implant and 1 had been sterilized.

Findings

Lack of autonomy

The most salient feature of the participants' responses regarding their use of contraception was a lack of autonomy. Factors contributing to this were a lack of knowledge about contraception and reproduction. In addition the women reported playing a generally passive role in their interactions with doctors. Consequently they felt that the important decisions about their contraceptive use were largely made by others. These themes are explored below.

Knowledge

The women reported that their primary sources of information about contraception had been learning disability services, mainly education, day or residential services. Although all had received some information about contraception, for many it had been 'too early' i.e. while they were still at school and not sexually active. However, for others it was 'too late', with two

women specifically stating that they had not been told anything about contraception until after they had become pregnant.

There was a general lack of knowledge about available methods of contraception, with a third of the women not knowing about any forms of contraception other than those they had direct experience of themselves. Of the remaining two thirds who had heard about at least one other method than their own, this was usually the Pill if they were using Depo-Provera and vice versa.

The women were asked whether they knew anything about how their contraception worked and the majority did not know and could not hazard any guess. However, some could give some basic description which was broadly accurate e.g.

'It's got some sort of chemical that goes all around your body'.

The woman who was sterilized could only say, perhaps not entirely unreasonably, that she did not know how she had been sterilized because 'they put me to sleep!'

As well as lacking knowledge about contraception, half the women also lacked basic knowledge about reproduction. This is noteworthy because of the women's relatively high levels of ability and social functioning. Nevertheless, areas of knowledge which were missing or patchy included not knowing about the menopause and that this signified the end of a woman's fertility, not understanding the link between fertility and the need for contraception, and (in one case) not even realising that sex was necessary for pregnancy.

The women were asked why they had been prescribed contraception. By far the majority said it was to avoid pregnancy, whilst some said it was to regulate their periods. Of those who said it was to avoid pregnancy, only a minority gave a clear indication that they were sexually active. Others were ambiguous and some explicitly said they were not sexually active. One woman clearly said that she had been prescribed contraception because she was thought to be sexually vulnerable:

'Wwld²) The managers were mentioning about it, and they thought it would be a good idea if I like tried to see if I can go on it, because I'm a vulnerable person really, and.....'

MM) Right, they thought you were vulnerable?

Wwld) Yeah, and then they think that some men might think I was an easy target...

MM) Yes, sure. Did you agree with them that you were vulnerable?

Wwld) Yeah'

Despite being the only one to explicitly acknowledge this, it seems highly likely that this was also the case for some of the other women, especially those who were given contraception from a very young age (see discussion below).

The women were asked what they thought might happen to them if they stopped using contraception: the majority said they might get pregnant, but some did not know. Of those who were concerned about a possible pregnancy, less than half were definitely sexually active. A small number of women clearly indicated that they were not having sex with a man,

but were nevertheless still worried about pregnancy. This is an example of the lack of basic knowledge alluded to above.

Medical consultations

Only a small number of the women went alone to their medical appointments. For most, it was the norm to be accompanied by either staff in learning disability services or their mothers (and, in one case, a boyfriend). In addition, some of those who did go alone would have preferred to have been accompanied. Only two women said they were happy to see the doctor on their own.

Of the large majority of women who were accompanied to see a doctor when they got contraception, all but one were happy with this. The women generally expressed views suggesting that they liked having someone else there to boost their confidence, e.g.

- 'I feel a bit nervous going on my own'.
- 'To give me a bit of support'.
- Or they liked it because they felt less vulnerable e.g.
- 'It makes me feel more safe'
- 'I like an adult there with me' (said by a woman aged 25).

However the most commonly given reason for wanting to have someone with them was that the staff member or relative could act as a kind of intermediary or interpreter:

- 'They can put things straight for me'
- 'Sometimes I don't understand it, so they have to explain it to my carer, so they can explain it to me easier'
- 'If the doctor says anything, my carer will basically remember or write it down for me'.

The only woman who was not happy about being accompanied to the doctor by staff, was a woman whose male keyworker had accompanied her. She distinguished between being happy to have him there for routine appointments related to her diabetes, but not for more private things. Her service seems to have been especially insensitive in providing her support, as she had her Depo-Provera injections in her bottom:

- 'I feel embarrassed...I can't help it, when you've got a man sitting in with you...how would you feel?'

This particular woman, who was Black British from an African-Caribbean background, felt her service and her keyworker did not appreciate some important cultural differences:

- 'When I talk to D. [keyworker], he says 'look at me when you're talking to me', but I can't look men straight in the eyes and talk to them. I get embarrassed. I'm a married woman and I get embarrassed, and he says don't get embarrassed with me. But I can't help my feelings.'

The importance of providing culturally sensitive services to people with learning disabilities from minority ethnic

backgrounds has long been recognised (Baxter, 1995; Williams, Keating, & Nadirshaw, 2002), but examples such as this suggests that good practice is not always followed.

A large majority expressed a preference for seeing a female doctor, with some expressing a very strong preference (see also McCarthy, 2002; Broughton & Thomson, 2000). Most women felt this way because it was simply more comfortable for them to talk to another woman:

- 'It's easier'
- 'I'd be embarrassed with a man'
- 'I wouldn't open up with a man'.

But for some women it was clearly more than embarrassment and they indicated that they felt vulnerable with male doctors:

- 'If it's a bloke, you don't know who they are'
- 'We women feel safer with women doctors, but if they are not around, we can always say no...sometimes I just say I'd rather wait until my lady doctor comes back'.
- 'I have to have a lady doctor. I wouldn't be safe with a man doctor, not touching me down below'.

Others questioned the ability of male doctors to treat 'women's problems':

- 'A man don't do nothing...they don't listen'
- 'Women doctors understand how the woman feels like and understand what conditions they're in, because when you see a man they don't know what condition a woman is like, so they won't understand, they're not a woman themselves.'

Research on women in non-disabled populations also shows that women generally prefer women doctors for what might usually be understood as 'women's health issues' e.g. related to menstruation, menopause, gynaecology, contraception, breast and cervical screening, etc. (Van den Brink-Muinen, De Bakker, & Bensing, 1994; O'Flynn & Rymer, 2002).

The women were asked to recall what was actually said during their consultations. When asked what kind of questions the doctor had asked them, most women either could not remember or said the doctor had not asked them anything. When asked what kind of questions they themselves had asked the doctors, the results were quite striking, as the vast majority said they had not asked anything, either in the initial, or subsequent, consultations. One woman gave the impression that very little communication took place at all between her and the medical staff when she went to get her Depo-Provera injections:

- MM) Do they ever ask you any questions?
- Wwld) No
- MM) Do you ever ask them any questions?
- Wwld) No.
- MM) Does your keyworker ask questions?

Wwld) No

MM) Do they speak to you?

Wwld) No

MM) Do they speak to your keyworker?

Wwld) Yeah, they do.'

The passivity of many of the women which is implied by the above findings, was directly expressed by some participants:

'I don't ask, I just go and have it, I don't ask'

'I just let them get on with it'.

None of the women had been given any *accessible* information about contraception by medics, although some had been given leaflets aimed at the general population, which were way above their reading and comprehension level. As most people with even mild and moderate learning disabilities find written materials hard to understand, the importance of making information accessible is clear (Canadian Association for Community Living, 1997; Mencap, 2000). All the women agreed they would have liked to have had accessible materials to take away. However, none of the women, nor their advocates, seemed aware of their legal right to accessible information under the Disability Discrimination Act 2005 and none of the doctors we contacted for a separate study (McCarthy & O'Neill, in preparation) seemed aware of their statutory obligation to provide it.

Decision making

The women were asked who had made the decision for them to have contraception and very few said they had decided themselves. Most reported that the decisions were made by GPs, staff in learning disability services, and parents.

The women were asked how long they thought they would use contraception for. Most, judging by their hesitancy and tone of voice, seemed a bit perplexed by this question and implied they would just carry on. The majority could not think of a single reason why they might want to stop. One, and only one, woman said she would stop using contraception if she was no longer sexually active. This is a very striking finding and the fact that the vast majority of these women with learning disabilities did not connect their contraceptive use with their heterosexual activity or lack thereof, is a cause for concern (see below for further discussion).

The women were also asked to consider what they would do if, for whatever reason, they did want to stop using contraception, i.e. how would they go about it? The majority said they would have to ask someone in authority e.g. the doctor or nurse who gave them the injection, staff or a parent. As well as most of the women thinking it was not within their own control to stop using contraception, some of the more autonomous women said that they would expect some opposition if they decided to stop, e.g.

'my dad would have something to say about it'.

It was also apparent that when a person in authority did challenge what a woman said she wanted, the challenge was accepted by the woman:

'Wwld) When I said to my nurse to come off it, she was telling me to stay on it.

MM) Why do you think that is?

Wwld) I don't know, I didn't ask her.'

Some women seemed to imply that 'having to' ask staff or relatives was not necessarily about asking permission, but rather it was seeking the advice of people of who were better informed (although clearly for many women it might be hard to ignore any such advice). For others it was much clearer where the power lay:

'They're the carers, they have responsibility for me'.

These findings support those found by others, such as Keywood et al. (1999) who found many women with learning disabilities implicitly rejecting the idea that they might make their own decisions about their reproductive health care.

With regards to autonomy, it was not a wholly negative picture and there were examples of when choice was exerted by the women. As the findings above show, some women, albeit a minority, did choose to use contraception and did choose which method they wanted. Two women each had one child and were very actively choosing not to have any more. One woman described how she had resisted attempts to get her to have an abortion:

'They did try to get me to have an abortion, but I said no...I said I'm a church believer and I wouldn't do that to the church.'

What these women had in common was they were amongst the most mildly intellectually disabled and they lived independently, either alone or with a partner. In other words they were not under the direct influence of parents or staff.

Discussion

Depo-Provera

The disproportionate use of Depo-Provera with women with learning disabilities, including those who are not sexually active, has been recognised for some time and in a number of different countries (Egan, Siegert, & Fairley, 1993; Welner, 1997). Once again it is confirmed by this study. It was used by over half of the women interviewed and in a separate study, over half of doctors surveyed said it was their first choice of contraception for women with learning disabilities (McCarthy & O'Neill, in preparation). This compares to less than 4% of women in the general UK population who choose to use this method (Office for National Statistics, 2005). Only one woman in this study had a contraceptive implant, but they are still relatively new in the UK. Given that, like Depo-Provera they do not require the user to actively do anything to regulate her own fertility, it is reasonable to expect that they

will, in time, be similarly over-used with women with learning disabilities.

Why should we be concerned about the widespread use of Depo-Provera with women with learning disabilities? It is, after all, an effective method of contraception. But efficacy is not the only consideration. If it were, we should expect to see much higher numbers of women in the general population using it. Depo-Provera clearly has side effects for many users, both in the short term (e.g. weight gain, irregular breakthrough bleeding, mood disturbances) and long term (e.g. risks of osteoporosis). It also has after effects, most commonly a delay in the return of normal menstruation and fertility. Unlike all other forms of contraception, it cannot be reversed once it has been injected. Therefore whatever side effects may be experienced, will have to be endured for the whole of that treatment cycle i.e. 3 months.

Depo-Provera and contraceptive implants are, like IUDs, methods of contraception controlled by the medical profession, not by the users of them i.e. once inserted or injected, there is nothing for the user to do. Oral contraceptives and barrier methods rely on user compliance, whereas injections and implants do not. Therefore the danger of them is 'their potential to increase providers' control over clients' choice' (Thompson, 1996: 1393). As demonstrated by some of the women in this study, it is not always easy to stop using them, as requests to do may be met with challenges. This is not a problem confined to women with learning disabilities; other disadvantaged women who have been targeted for their use (e.g. women in developing countries) have found some providers of implants unwilling to remove them (Thompson, 1996). Even in developed countries such as the UK, US and in Europe, women who are poor, from ethnic minorities and who are socially marginalized have been targeted for the use of long acting contraceptives (Hartmann, 1995). Where population control and social control of certain groups form part of the agenda, questions need to be asked, and challenges raised, about the over-use of certain methods of contraception, for it is clearly no longer a private medical concern between individual women and their doctors.

Health care practitioners and others who support women with learning disabilities have a responsibility to outline both the advantages and disadvantages of any given method of contraception. Given the overuse of Depo-Provera demonstrated in this research and elsewhere, it is hard to see how this can be the case. Despite its undoubted efficacy, there is something about it which makes it an unattractive option for the vast majority of women of ordinary intelligence. This leads to the suspicion that the potential disadvantages are not being spelled out to women with learning disabilities quite as clearly as they might be. This is a serious matter and not one confined to women with learning disabilities; in relation to women in developing countries, *contraceptive abuse* has been defined as direct (e.g. giving contraception against women's will or without their knowledge) or more subtle (e.g. giving biased information about a method, such as emphasising its effectiveness while playing down or not mentioning its adverse effects) (Richter, 1996).

'Just in case' and 'Overkill'

One of the interesting and important findings of this research project is confirmation of the fact that contraception is given to women who are not sexually active (and who also

do not experience menstrual problems). This has been reported before (see Introduction above) and so may not appear particularly noteworthy, but I believe it is because it emphasises that this practice is not a historical, institutional problem, but very much a contemporary, community based one.

The findings of this project demonstrate clearly that in some cases there is no clear link – either in the minds of the women themselves or their carers and doctors – between actual sexual activity and the need for contraception. Some women in this study who were not sexually active were still worried that they might get pregnant if they stopped using contraception. It is almost as if concerns about a woman getting pregnant are enough in themselves to get her pregnant. They seem to have forgotten, and those around them were not reminding them, that it does take vaginal intercourse with a man for a woman to get pregnant.

A 'just in case' mentality seems to be in operation and this is not an appropriate or acceptable long term strategy for most women. Women in this study stated beliefs that being sexually inactive was no barrier to using contraception, e.g.:

'On the injection I never once wanted to do anything, never once wanted to sleep with anybody.'

'I don't have to have sex to be on it, you could be on the injection for lots of different reasons, but I like to be safe. Who knows, one day, you might want to and if you're not on it...'

Where does responsibility lie for such attitudes? It is of course possible that women with learning disabilities come to this 'just in case' attitude themselves. But women generally gave a clear impression that this mindset had come from carers, e.g.:

'They said just in case one day I find a nice gentleman... they said just to be on the safe side, stay on the injection just in case.'

The woman quoted here was, in fact, 44 years old, with a host of serious physical and mental health problems, which effectively precluded intimate relationships with anyone. She had also experienced sexual and physical violence in previous relationships, which made her very wary of men. She lived in a staffed group home with 24 h support. The chances of her meeting a man and wanting to start a sexual relationship with him so quickly that there would not be time to arrange contraception seems remote. Research elsewhere has shown that "pregnancy is not a substantial risk...for women with high support needs" (Grover, 2002: 108).

For some women with learning disabilities who genuinely do have a lot of sexual partners who change unpredictably, who do not want to have a child and who cannot be relied upon to seek contraception in a timely fashion, then perhaps the 'just in case' approach can be justified. But even for these women, there are other alternatives, which could, and should, be explored. For example:

- they could be taught about emergency contraception i.e. the 'morning after Pill' (which can be used up to 72 h after

intercourse) and the emergency IUD (which can be inserted to up to 5 days after) and encouraged to seek it if they have exposed themselves to risk of pregnancy. (NB In the service user advisory group, which consisted of some very able women with a lot of experience of contraception, as well as some limited experience of pregnancy, none of the women had heard about the morning after Pill.)

- Whilst it is of the utmost importance to guard against covert or coercive sterilizations of women with learning disabilities, not least because of the historical legacy of such eugenic practices, nevertheless surgical options should not be ruled out for those who do want them. After all, in the UK, sterilization is chosen by 10% of women and 12% of men in the general population (Office for National Statistics, 2005). One woman in this study, aged 30, had requested, and been given, a sterilization and she was very happy with this outcome. Another had asked her doctor for a sterilization, but had been told that, at 28 years old, she was far too young. This woman had, in addition to moderate learning disabilities, serious physical health problems which meant she should not get pregnant and no desire for children, yet her serious request to her doctor was not heard and she continued to be given Depo-Provera.
- Similarly, whilst needing to guard against women with learning disabilities being pressured into having terminations that they do not want, nevertheless they should be available to those who do want them. It is recognised that for some women with learning disabilities, there will be moral, religious or cultural prohibitions on abortion. But we must also recognise that, despite people's different views on it, it is a commonly performed procedure in the UK, where some 185,000 women have abortions every year (Dept. of Health, 2005).
- Women with learning disabilities after their mid-30s could be given the same information as other women about the likely decline of their fertility at this age. After all, at the beginning of the 21st century, non-disabled women cannot pick up a newspaper or magazine without reading about the sharp decline in their fertility after 35 (see Bewley, Davies, & Braude, 2005 for an example of a report which sparked a media flurry) and a thriving assisted reproduction industry exists to help them if they do want children. If women with learning disabilities were as aware of this decline in their fertility as other women, then their use of contraception well into middle age would not be as common as this research suggests may be the case. From this relatively small sample of 23 women, the situation of those over 35 was as follows:

37 year old on Depo-Provera
 38 year old on Depo-Provera
 44 year old on the Pill
 44 year old on Depo-Provera
 44 year old on Depo-Provera
 47 year old on Depo-Provera

Doctors need to take responsibility here. Whilst women with learning disabilities may not be aware of the likely decline in their fertility, doctors obviously do know this. Yet in this study three doctors were giving Depo-Provera to women in their mid-late 40s, a situation which might reasonably be

described as over-cautious at best and 'overkill' at worst. As long as such prescribing practices remain, doctors will continue to find themselves accused by disability advocates as regarding disabled women's reproductive capabilities as 'a threat' (Waxman, 1994:156). Those who support women with learning disabilities, such as staff and family carers, could also help by questioning whether there is a genuine likelihood of pregnancy and therefore whether contraception is really needed.

There is an inherent danger in focussing interventions solely on contraception. When pregnancy prevention is prioritised over and above everything else it can overshadow a woman's need for adequate protection from sexual abuse and from sexually transmitted infections (STIs) (McCarthy, 1999), either of which can be more damaging to women in the long term than an unwanted pregnancy. This is not to be complacent about the effects of unwanted pregnancy, as they are potentially serious. But so is being infected with HIV or other STIs or being raped.

We also need to acknowledge that for some women with learning disabilities, like other women, an unplanned pregnancy may not necessarily be an unwelcome pregnancy. Society needs to invest more resources into supporting women with learning disabilities to become, and remain, good parents to any children they do have (Tarleton & Ward, 2007). If this were done, then some of the fears about women with learning disabilities becoming pregnant could perhaps be somewhat assuaged.

Exercising choice and control

The findings in this research project demonstrate that when it comes to making their own decisions about contraception, most women with learning disabilities feel that this did not happen for them. It was similarly difficult for women with learning disabilities to feel that they had control over stopping contraception. As the findings above show, most women did not know how long they might use contraception for, could not think of reasons why they might stop and did not think it was within their own control to stop. All of these point to a lack of a sense of personal agency, and therefore an unsatisfactory state of affairs.

As with so many other areas of the lives of people with learning disabilities, a balance needs to be found between protection and empowerment (McCarthy & Thompson, 2004). For many years certain methods of contraception have been given to women with learning disabilities precisely because they require little or no "active user participation" and this has been seen as a good thing (Chamberlain et al., 1984:449). This research project has demonstrated that this practice is still very much alive and well in the 21st century. Whilst it may be appropriate for some women with learning disabilities, there is a need to challenge such practices on a collective level and emphasise the need for women with learning disabilities to enable to exercise as much choice and control as they possibly can. This will entail a change of attitude and an increase in resources to support women through this process. The alternative is to remain with the status quo and accept that many women with learning disabilities will effectively be allowed no sense of personal agency for most, or the whole, of their reproductive lives.

Questions of social inclusion are pertinent to this discussion: if women with learning disabilities are not being enabled to exercise choice and exert control over what happens to their bodies, then their civil rights and their potential for achieving independence may be compromised. It has been argued that the way we practice healthcare is “a means by which we demonstrate the value we place on other people's lives” (Brooke, 2000:12). It is hard to escape the conclusion that negative attitudes, values and stereotypes about the reproductive capacity of women with learning disabilities influence decisions taken about their contraceptive needs. When these negative attitudes are combined with authority and power, they are a potent combination.

Constraints on 'free choice'

Whilst some women with learning disabilities did report making choices about contraception, it was also the case that the circumstances they found themselves in meant their *real* ability to make choices was seriously compromised. Legally and ethically, doctors assessing patients' ability to give informed consent to treatment need to satisfy themselves that, amongst other things, patients are making a 'free choice (i.e. free from pressure)' (BMA 2001:26), yet this research project has revealed a number of ways in which women's choices are constrained. One obvious way is starkly illustrated by the young age at which some of them began using contraception. In this relatively small sample of 23, 4 women started using contraception under the age of 15 (2 were age 12, 1 was 13 and 1 was 14). All were taken to the doctors by their mothers and it is clear that in these circumstances choosing not to use contraception would be very difficult for the individual girls concerned. Similar dynamics arise for adults with learning disabilities who are still under the influence of their parents or paid carers.

Another constraint on women's choices to start contraception was illustrated by the two women who described having the make decisions about contraception at the same times as having an abortion:

'Before I moved here, I was pregnant, then they took me to hospital to have it done, the operation, and then they said you either be on the Pill or have an injection. So I said an injection. And so I've had it for years.'

Requiring women to 'choose' contraception at a time of emotional and physical vulnerability should be seen as a potentially coercive, and therefore, unethical practice.

Other women's choices were constrained by fears of losing their service. One woman said that the reaction of the manager of her group home when she was pregnant was to 'have a go' at her and 'she tried to put me away'. Others said, referring to staff (one of whom was present during the interview):

'If I was pregnant, you'd go mad wouldn't you? You'd go crackers.'

'K. said it, she said they'd get rid of me if I was pregnant. To a house on my own so I'd have to look after it.'

Women's fears of losing their services if they become pregnant have been noted elsewhere in the literature, with suggestions that what is needed is a whole systems approach to exploring the all the alternatives for women with learning disabilities in this situation 'rather than working from a framework of restrictions' (Stinson et al., 2002: 24).

Other women feared losing family approval or support if they became pregnant:

'My mum doesn't want me having babies, so she got me to use the injection'

'I have the job so I can't be blamed for getting pregnant'.

Some women's current and future choices were obviously constrained by their past experiences, most obviously by having their own children taken into care and seeing this happen to others. This is clearly traumatic and obviously colours the decisions some women make:

'What's point of having a baby, when you've already had one taken away?'

Such concerns are also likely to be uppermost in the minds of those who care about, and care for, women with learning disabilities; they too want to avoid same thing happening again.

The social and political significance of the women's experiences

To return to the introductory point of this article, namely the almost total absence of women with learning disabilities from feminist and disability right discourses, we can see that analysing their experiences is a complex matter. Some feminist commentators argue that we can best understand by acknowledging that 'disabled women and girls live at the corner of disability and womanhood – with two 'minority' identities, a double dose of discrimination and stereotyping and multiple barriers to achieving their life goals" (Waxman & Wolfe, 1999:3). Others (e.g. Morris, 1992) refute the usefulness of the concept of 'double discrimination' for disabled women. Arguably what is needed is to ground the experiences of women with learning disabilities within a socio-political critique of power and powerlessness, particularly as related to gender and the gendered body (Burns, 2000). For there is no doubt that in the past few decades there has been significant progress in many women's rights to control their own fertility *and* in recognising the rights of people with disabilities. Yet still women with learning disabilities seem to have been left behind. There are a number of reasons for this. Firstly, the liberal ideologies of autonomy and independence, which fuelled both feminist and disability rights campaigns, do not sit well with the needs of women with learning disabilities, most (though by no means all) of whom will always rely the support of others to live their lives (Garland-Thomson, 2001). Secondly, the legacy of past eugenic ideologies and practices has far from disappeared. Although the strategies and technologies to prevent women with learning disabilities from having babies have evolved, the fact remains that parenting is still largely viewed as undesirable for them and therefore something to be avoided. Those

who have power, authority and influence over women with learning disabilities see it as their responsibility to try to prevent them from bearing children (Waxman & Wolfe, 1999). The heavy-handed use of contraception described in this research is one response to that. Thirdly, the extreme vulnerability of girls and women with learning disabilities to sexual abuse plays an important part. Prevalence rates as high as 79% (Stromsness, 1993 p. 142) and 82% (McCarthy, 1999 p. 210) have been found and whilst not all sexual abuse involves vaginal penetration, much of it does (McCarthy & Thompson, 1997) and therefore exposes them to risks of pregnancy. As this research and other work (for example McCarthy, 1999) demonstrates, it is the fear of girls and women with learning disabilities being sexually abused that directly leads to some of them being given contraception. They themselves may have little or no say in the matter, nor indeed any understanding, or even knowledge, of what is happening. Following on from this is the fourth reason for the particularly disempowered position of women with learning disabilities, namely their lack of 'voice' (Traustadottir & Johnson, 2000). Because of the nature of their impairments, often involving difficulties in conceptualising, remembering and communicating, women with learning disabilities are perhaps uniquely disadvantaged when it comes to conveying their own experiences and making connections with others. Gradual progress is being made, however, with published work both by self-advocate groups (Group of Women with Disabilities, 1996; Thursday Club, 2002) and collaborations between feminist academics and women with learning disabilities (Atkinson et al., 2000; Traustadottir & Johnson, 2000.) Such work gives a public voice to those whose experiences are more usually hidden. However, as well as a lack of 'voice', the reality is that many women with learning disabilities also live in conditions of material, social and educational deprivation (Noonan Walsh, 2002). Seen in this way, their isolation from the wider world, and from the improvement in circumstances that others may have enjoyed, then their lack of agency generally and specifically in relation to their sexual and reproductive lives, becomes easier to understand.

Conclusions

"Increasingly, health care recipients are expected to be active partners with their care providers – communicating effectively and advocating for themselves to ensure that their care needs are met" (Parish & Saville, 2006: 258). It is not hard to see how women with learning disabilities are disadvantaged in this process. In order to move to a position where women with learning disabilities are enabled to make more choices of their own, many things at both policy and practice level need to change. From the experiences of women in this study and from previous work that puts their experiences into context, such changes might include:

- Understanding that women with learning disabilities share much in common with other disadvantaged groups of women when it comes to a denial of their reproductive rights (Kallianes & Rubinfeld, 1997). Similarly understanding that they therefore would benefit from being included in alliances to gain strength from shared opportunities to overcome oppression (Williams & Nind, 1999).
- Negative and generalised attitudes about women with learning disabilities' inability to care for their children need to be rigorously challenged (Booth & Booth, 1998) and better support systems put in place (Tarleton, Ward, & Howarth, 2006).
- Doctors and other health care practitioners need to be better informed about the lives, needs and capabilities of people with learning disabilities. Evidence suggests that their current professional training, at undergraduate level, postgraduate level or during their continuing professional development does not adequately prepare them to serve this group of patients (Dovey & Webb, 2000; Hogg, 2000).
- Learning disability services need to develop policies on contraception use which require them to question methods of contraception which are disproportionately used with women with learning disabilities, e.g. Depo-Provera. This is not to suggest that they are always inappropriate for women with learning disabilities, but simply to question whether they should be used with so many and to explore possible alternatives. Regular reviews of contraceptive use should also be implemented, so that the *actual need* for contraception can be reviewed. This could also be done as part of regular service user reviews within learning disability services (as happens with other forms of medication), obviously with sufficient safeguards to respect privacy and confidentiality.
- Girls and women with learning disabilities need access to better sex education (McCarthy, 1999), which would include information on the range of contraceptive options available. Women with learning disabilities need to be specifically encouraged to question, or at the very least to ask questions about, what is suggested as being in their best interests. For example, one woman in this study said

'They asked me if I wanted the implant and I said yes there and then, I didn't have to think about it.'

Women need to know that they can, and should, think about it.
- There needs to be priority given to producing and distributing accessible information on reproductive health care, using pictures and easy to read text (see for example Women's Health, 2002).

If women with learning disabilities lack information about contraception, and are not enabled to make choices, then this "serves to perpetuate a lack of control over reproductive choices just as forced sterilization did in the past" (Dotson, Stinson, & Christian, 2003: 198). The phrase 'informed compliance rather than informed choice' (Stapleton, Kirkham, & Thomas, 2002: 639) has been used in other healthcare contexts and not in relation to people with learning disabilities. However it aptly describes the situation of many women with learning disabilities when decisions are being made about their reproductive health care and the time has surely come to change this.

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Endnotes

¹ Article 12 relating to the right to marry and found a family and Article 14 on the prohibition of discrimination are relevant here.

² Wwld denotes a woman with learning disabilities. MM denotes the interviewer.

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