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Contraceptive decision-making and women with learning disabilities

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Abstract

This article explores contraceptive decision-making for women with learning disabilities. It sets the historical context of reproductive control by highlighting former practices which overtly aimed to prevent women with learning disabilities from conceiving. This is contrasted with a current legislative framework that strongly endorses the human and reproductive rights of women with learning disabilities. The article presents findings from a small scale, UK- based survey that invited third parties involved in supporting women with learning disabilities with contraceptive decision-making to share their views and experiences. The survey indicated apparent continuities in practice, showing that key decisions over contraceptive care are often made by other people and not by women themselves. The increasing evidence of a gap between policy and practice is explored; this suggests a need for further research, including studies to explore the experiences of women with high support needs where there may be particular issues in relation to the management of menstruation, decision-making and capacity to consent.

Key words: contraceptive, decision-making, learning disabilities

Contraceptive decision-making and women with learning disabilities

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, forthcoming).

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 needs¹ remains particularly under-researched (McCarthy, 2010: 294).

We set the historical context of reproductive control by highlighting former practices which overtly aimed to prevent women with learning disabilities from conceiving. This almost ‘wholly negative’ (McCarthy, 2009b: 198) historical context is contrasted with a current legislative framework that strongly endorses the human and reproductive rights of women with learning disabilities. We then outline existing evidence regarding contraceptive usage by women with

¹ Following Beamer and Brookes (2001) the authors use the term ‘high support needs’ to refer to ‘people with learning disabilities who have extra needs. Some people have physical impairment, others health needs and behaviours labelled as challenging’ (p10). In relation to the Open University survey that is discussed in this article, individuals described by respondents as having ‘severe’ or profound and multiple learning disabilities’ (PMLD) are referred to collectively as people with ‘high support needs’.

learning disabilities, and present findings from a small scale, UK- based survey that invited third parties involved in supporting women with learning disabilities with contraceptive decision-making to share their views and experiences. We conclude with a discussion of apparent continuities in practice, despite substantial policy changes in relation to sexual relationships and conception for women with learning disabilities. Concerns identified by families, front line staff and practitioners are also discussed. Finally, the increasing evidence of a gap between policy and practice is explored; this suggests a need for further research, including studies to explore the experiences of women with high support needs where there may be particular issues in relation to the management of menstruation, decision-making and capacity to consent.

Review of the literature

Reproductive Control: the historical context

A major motivation for the early twentieth century legislation which created a national network of learning disability hospitals was to segregate ‘defectives’ and prevent them having children (Jackson, 2000; Thomson, 2010). This approach is exemplified by the words of the 1908 Report of the Royal Commission on the Care and Control of the Feeble-Minded, ‘*the only remedy is to place persons so suffering under such restrictions as to make procreation impossible*’ (Sixty-Third Report of the Commissioners in Lunacy 1909: 4–5; May and Simpson 2003: 29, cited in Monk, forthcoming: 39). As such, the issue of contraception for women with learning disabilities is a sensitive subject.

During the first half of the twentieth century, institutionalisation, with strict segregation of the sexes grew rapidly throughout the UK, Scandinavia, the USA, Canada and Australia. Some countries, such as Denmark, Norway, Finland and Sweden enacted laws to prevent people with learning disabilities from marrying. Others, for example Iceland, Sweden and states within Canada (Malacrida, 2013) and the USA (Monk, forthcoming) legislated to allow involuntary sterilisation. In Sweden, 60,000 people with learning disabilities, mostly women, were legally sterilised between 1935 and 1976 (Engwall, 2004), often as a precondition for leaving the institution. Other countries, like the UK, never legislated to permit involuntary sterilisation, but there are indications that sterilisation was in widespread use until the later part of the twentieth century (Stansfield et al, 2007; Tilley et al 2012; Walmsley et al., forthcoming). This nurse recalled practice in the learning disability hospital where she worked in the 1970s and 1980s:

What I remember is women being sterilised because they had had a baby or there was the risk because of promiscuous behaviour, they would be sterilised, that was before the decision was made that it would be a court decision, the parents would just give permission. (Learning disability nurse with 40 years service remembering her time at a long stay hospital, speaking in an oral history group reminiscence session with one of the authors, England 2014, unpublished oral history data).

Community-based care, normalisation and contraception

By the end of the twentieth century legislation permitting widespread involuntary sterilisation of women with learning disabilities had been repealed in Europe, North America and Australasia.

From the 1950s onwards there was a shift in policy from institutional to community-based care, fuelled in part by increased emphasis on equality and civil rights and increasing evidence that given the right education and support people with learning disabilities could learn new skills and become more independent (Tizard, 1964). From the 1960s philosophies of normalisation (Bank-Mikkelsen, 1969; Nirje, 1969) and its later North American re-formulation Social Role Valorisation (Wolfensberger, 1972; Wolfensberger, 1983) exerted substantial influence on the development of community learning disability services. These approaches stressed that people with learning disabilities should experience conditions as close as possible to the norms and patterns of the mainstream society; including the right to live in mixed sex environments, form relationships and marry. However, although Wolfensberger, one of the key proponents, advocated 'social-sexual fulfilment' as a right, he advised that, in North America at least, it must be achieved via childless marriage, 'because the North American public will not now approve, and probably never will, childbearing by those unlikely to be capable of children rearing' (Wolfensberger, 1972: 171). Monk (forthcoming) highlights the content of a UK publication from the National Society for Mentally Handicapped Children that, whilst advocating sexual rights, stated that respect for the welfare of potential children required that 'the mentally retarded should not be persuaded of their right to procreate' (Lee, 1974: 7-9, cited in Monk forthcoming).

In this way we see in the midst of progressive policies a continuation of negative attitudes that resulted in many people with learning disabilities continuing to lose their parenting rights. Lee (1974, op cit) observed that modern birth control had rendered institutional incarceration of women with intellectual disabilities obsolete. His remark implies that contraception represented a new, more effective method to prevent women with intellectual disabilities becoming mothers.

Monk (forthcoming) suggests that as institutionalisation had earlier denied women with learning disabilities control of their reproductive lives, so contraception continued to do so with medication used to manage fertility in community-based settings.

The Current Context in the UK: A rights based approach

The Human Rights Act (1998) came into force in the UK in 2000, reinforcing a rights-based approach within health and social care and a duty to ensure that everyone receives the benefit of the law. In terms of decisions about parenting and contraception articles 2, 3, 8, 12, 14 and 17 are of particular relevance. The 2006 UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by the UK in 2009, also upholds disabled people's rights to found a family and to decide on the number and spacing of their children (Article 23 <http://www.un.org/disabilities/convention/conventionfull.shtml> accessed 2.3.2014).

Individual countries are also committed to supporting people's rights to enjoy relationships and to choose whether or not to have children. In England people with learning disabilities were closely involved in the groundwork for *Valuing People*, the English policy framework for adults with learning disabilities introduced in 2001. *Valuing People* emphasised the need for accessible sex education and information about relationships and contraception: a priority reiterated in the updated version *Valuing People Now* that explicitly stated:

People with learning disabilities have the choice to have relationships, become parents and continue to be parents and are supported to do so (DH 2009: 92)

The Mental Capacity Act 2005 (England & Wales), enacted in 2007, introduced a legal framework in which it is assumed that an adult has capacity to make a decision unless it is established, according to clearly specified criteria, that he/she does not (Mandelstam, 2009). The Act requires that all practicable steps be taken to help the person make the decision and specifically makes reference to providing information in a simple format (Rowlands, 2011). Capacity is regarded as decision-specific, and where it is established that a person lacks capacity to make a particular decision, then whoever makes the decision on the person's behalf must do so in the person's best interests, and must work out those best interests by considering a list of key factors (the 'best interests checklist'). These include, amongst other things, consulting a range of people involved in the care of the person. Those prescribing contraception, therefore, cannot rely on the informal capacity judgements of others (McCarthy, 2010a: 300), and must follow the best interests checklist when women are assessed to lack capacity to decide upon contraception for themselves.

Balancing rights with protection

Fyson (forthcoming) argues that progress with policies to enhance reproductive rights for women with learning difficulties has been complicated by a simultaneous sharp increase in awareness of their vulnerability to sexual abuse (McCarthy and Thompson, 2010). Fyson emphasises the impact of studies in the mid-1990s that highlighted adults with learning disabilities as victims of sexual assault (Brown and Turk, 1994; Brown et al., 1995; Craft and Churchill, 1997). A reason commonly given for placing women on contraception is to ‘protect’ them from sexual abuse (McCarthy, 2009a). In a Taiwanese study one respondent commented:

My mother was scared that she might be ‘chi-fu’ (taken advantage of); so she made this decision (tubal ligation)...doing a tubal ligation would make her safe from pregnancy. (Chou and Lu 2011: 67-68)

The impact of concerns about vulnerability on contraceptive decision-making is recognised in the WHO statement on eliminating forced, coercive or otherwise involuntary sterilisation which states ‘parents or guardians may be concerned about avoiding unwanted pregnancy, because of vulnerability to sexual abuse’ (WHO, 2014: 6). However the report emphasises that sterilisation (through surgery or ongoing contraception) does not protect against sexual abuse and does not remove the obligation to protect against such abuse. Brown (2010: 4) discusses the danger that, in relation to people with learning disabilities, people tend to position themselves at either end of a continuum, advocating protection or choice ‘as if choosing one should deprive a person of another’. Yet, Brown emphasises, most non-disabled citizens expect to make choices about their sexual lives and to be protected from sexual abuse in equal measure.

Pring (2005), a journalist who investigated long standing abuse, including rape, at homes in the Longcare group in Buckinghamshire, England, in the 1990s also makes the point that contraception does not protect against the abuse itself, merely the pregnancy that may result. Indeed, administration of contraceptives under such circumstances may serve to protect the perpetrator of abuse. Pring noted:

Staff told me disturbing stories including how the GP had given contraceptive injections to at least five of Rowe's female 'favourites' one after the other in a toilet that led off the main reception area, while he continued sitting with Rowe who was sitting at reception. (2005: 4)

The way the General Practitioner (GP) operated, in public, meant that the women had no opportunity to raise with him any objections to the practice, or to tell him of the abuse. This casual practice had enabled the home owner, Gordon Rowe, to continue to rape the women without fear of any obvious consequences.

Despite the pronounced shift in the legal and policy framework outlined above, evidence to date indicates that for women labelled as learning disabled many of the issues which gave rise to segregationist policies have not disappeared (WHO, 2014). Anxieties regarding risk of abuse and the ability of women with learning disabilities to cope with pregnancy, labour and child-rearing endure among professionals, family members and women themselves (Anous and Feldman, 2002; Chapman et al., forthcoming), and concerns about child welfare and protection lead to many mothers with learning disabilities losing their children (Llewellyn et al., 2010). Although

applications to the courts for the sterilisation of women with learning disabilities continue to be considered (Stansfield et al., 2007; McCarthy 2009a, 2010a; Rowlands, 2011), the literature indicates that in the early 21st century, women's capacity to conceive and bear children is, in the main, controlled through social and contraceptive care interventions (McCarthy 2009a, 2010a; Tilley et al., 2012) rather than surgical sterilisation.

What is already known about contraceptive use and decision-making amongst women with learning disabilities?

There is little data available to ascertain the impact of rights-based policies on contraceptive decision-making practice with women with learning disabilities. Occasionally the topic of preventing women from child bearing hits the headlines, such as when a parent seeks to have their child sterilised through the courts (McVeigh, 2011). However, most decisions about contraceptive care have a much lower profile, and it is these day-to-day decision-making processes that we explore.

Contraceptive usage - Research evidence suggests that the pattern of contraceptive use amongst women with learning disabilities does not match that of other women of childbearing age, with higher levels of contraception being prescribed to women who are not sexually active (McCarthy, 2010a), greater reliance on long-term medication such as Depo-Provera (McCarthy, 2009a; Weiner, 1997) and frequent use of contraception to control menstrual problems (Carlson and Wilson, 1994; van Schroyen Lantman-de Valk 2011). McCarthy (2009a) interviewed 23

women with mild and moderate learning disabilities regarding their experiences of being prescribed contraception. Eleven out of twenty-three women were using Depo-provera. The use of barrier methods such as condoms remains very uncommon (Servais, 2002; McCarthy, 2010a).

Contraceptive decision-making: the context - In the broader context of choice and control over contraception, McCarthy's interview based research into contraception and women with learning disabilities (2009a and 2009b) indicated that contraception is prescribed at an earlier age and continues later than for non-disabled women, with an over-reliance on carers to communicate with doctors. McCarthy (2009a and b) highlighted a disregard for the health consequences of using Depo Provera for long periods (loss of bone mineral density and consequent increased risk of osteoporosis) and suggests that contraceptives are being used as a response to the danger of sexual abuse and rape; the 'just in case' (McCarthy, 2010b: 264) approach, justifying contraceptive interventions even amongst women who are not sexually active, on the basis that something might happen to them at a future point. McCarthy (2009a) also noted fear of the consequences of pregnancy; and that decisions concerning contraception are influenced by convenience for front line support staff in managing women's periods, a finding echoed in recent research in Taiwan (Chou and Lu, 2011). McCarthy concluded that her interviewees lacked autonomy or knowledge of alternatives, and played a largely passive role in determining whether to use contraception. The majority reported that they did not understand how their contraception works or why that method had been recommended. None had been given accessible information to support their decision-making (McCarthy, 2009b, 2010a).

McCarthy included a survey of 162 General Practitioners in her research into contraception (McCarthy, 2010a, 2011). The results highlighted that each GP had relatively few women with learning disabilities on their caseload and so lacked experience in supporting women with contraceptive decision-making. Findings indicate a low level of awareness of rights as opposed to perceived medical needs. 94.1% people were accompanied by a carer to consultations, which was welcomed by GPs as helping with communication and compliance, but showed little regard for women's right to make decisions without parental or paid carer influence.

Depo Provera was prescribed to 48% of the sample of women because they were regarded by GPs as unreliable users of the pill or other forms of contraception (McCarthy, 2009b). This contrasts with only 3% of the wider population choosing this form of contraception, and, suggested McCarthy, may indicate a disregard for the side effects of injectable hormonal contraception for women with learning disabilities. Overall there was a poor understanding of mental capacity legislation, with many GPs assuming that carers could give proxy consent to treatment. None mentioned the women's right to confidentiality.

McCarthy's findings are supported by other studies. In a Dutch study of 112 women with learning disabilities using contraception, Van Schroyen Lantman-de Valk et al. (2011) noted that only ten had possible sexual relationships. Like McCarthy (2009a), they also note the practice of contraception continuing after the menopause or when the likelihood of sexual relationships had passed.

In terms of contraceptive decision-making with women with learning disabilities there are many possible perspectives to take into account: the views of the woman herself, her partner or future partner, family members, front line staff, provider managers, GP's, social workers, and nurses, to name a few. Despite the availability of some community contraception services, the majority of contraceptive consultations for women with learning disabilities take place in GP practices (Rowlands, 2011). Yet numerous enquiries have highlighted barriers encountered by people with learning difficulties in accessing primary and secondary health care, including: institutional discrimination against people with learning disabilities (Mencap, 2007); a lack of awareness of the health needs of people with learning disabilities amongst primary care staff; and, a lack of attention to making reasonable adjustments to support the delivery of equal treatment as required by UK disability discrimination legislation (Michael, 2008; Heslop et al., 2013). Heslop et al (2013: 5) in their analysis of NHS care found 'professionals in health and social care commonly showed a lack of adherence to and understanding of the Mental Capacity Act'.

With the exception of McCarthy's research (2009a, 2009b), which took place prior to the enactment of the MCA, there is very little evidence available concerning the decision-making processes involved in learning disabled women's contraceptive care, and the attitudes, structures and stakeholders that shape such interventions. The survey reported below begins to explore some of these issues.

The Open University survey on contraceptive decision-making

The survey aimed to explore who decides about contraception for women with learning disabilities. It was funded by an Open University research grant. Part of a larger research programme which explores the issue of contraception and learning disability more widely, this survey was targeted at ‘third parties’, i.e. family members, advocates and health and social care practitioners. Through surveying third parties, we aimed to find out more about who was involved in making decisions about contraception; what types of contraceptive interventions were being prescribed; when contraception was being prescribed and for how long; and how interventions were being reviewed. The experiences and perspectives of women with learning disabilities will be gathered in the next phase of the research². The survey comprised 29 questions and a combination of multiple choice and open-ended questions were used generating both qualitative and quantitative data, as per figure 1, below.

Figure 1: Example of two questions from the survey (multiple choice and open ended free text)

Who initially raised the issue of using contraception?

Tick one box

1. The woman herself
2. The woman’s partner / potential partner
3. Parent

² In 2014 we undertook interviews with women with learning disabilities about their experiences of contraceptive decision-making. This phase of the research is funded by Open Society Foundations.

4. Other family member
5. Member of support staff (residential)
6. Member of support staff (day care)
7. Personal assistant
8. GP
9. Other medical practitioner
10. Learning disability nurse
11. Social worker
12. Friend
13. Other

Open Ended Question

Any other comments: Please tell us more about your views and/or experiences on the subject of contraception for women with learning disabilities

The survey gained ethical approval through The Open University's Research Ethics Committee in March 2012. Respondents were recruited through circulation of the survey on ten online mailing lists that concerned issues of disability and/or reproductive health. The survey was also circulated through The Open University's own extensive data base of contacts, including the Social History of Learning Disability Research Group, which includes academics, research students, practitioners, self-advocates and family members from across the country. We aimed to collect over 50 responses, providing sufficient data to explore emerging trends and for comparative purposes.

The survey was launched in April 2012 and closed at the end of June 2012. 90 completed responses were received and were included in the data analysis. Because of the relatively small numbers involved, quantitative data analysis software was not used. Responses were counted in Excel, and qualitative data included in the open-ended questions were analysed thematically.

The largest single group of respondents were learning disability nurses (25%), followed by paid care / support workers (19%) and family members, mostly mothers (17%). Respondents also included independent advocates, doctors, social workers and academics. Using the categories of ‘mild’ ‘moderate’, ‘severe’ and ‘profound and multiple’ (PMLD)³ respondents were asked to describe the degree of learning disability of the person with whom they had been involved in contraceptive decision-making. Responses were received in relation to 21 women with severe and multiple and profound categories. Little is known about the experiences of women with more severe and profound learning disabilities (referred to in this article as women with high support needs), including the impact of recently introduced Mental Capacity legislation on decision-making practice. In the light of this we report our survey findings in two parts:

Part 1 summarises the survey findings across all 90 respondents.

Part 2 focuses on responses received in relation to 21 people with high support needs. It should be noted that while these survey results represent a small sample, the data was sufficiently comprehensive to enable us to draw out some important findings which we believe have wider

³ The rationale for use of these labels was that they remain common within learning disability services. The same categories were also used by McCarthy (2009a and b, 2010b) in her research enabling comparison between findings.

relevance and applicability. In presenting our data we have thematically organised responses from a range of questions into key areas. These are reported under the headings below.

Findings part 1: Survey wide responses (responses received in relation to women with mild, moderate, severe and profound disabilities)

Who raised the issue of contraception and why?

The survey questions explored who first raised the issue of contraception and the age when this happened. Responses indicated that the majority of women began to discuss contraception, or to have it discussed, in late teens and twenties, which does not raise particular concerns although, as we report later, when we considered women with higher support needs specifically, it emerged that they tended to have contraception discussed at an earlier age (see Part 2 of our findings below).

In a minority of cases (15%) the issue of introducing contraception was first raised by the woman with learning disabilities. In most cases the subject was initially raised by residential support staff, followed by mothers, then support staff or GPs. Others reported as introducing the subject of contraception were learning disability nurses and social workers. These findings reinforce the views of women with learning disabilities interviewed by McCarthy (2009b, 2010a), the majority of whom reported contraception being suggested by others such as parents, GPs and staff, rather than initiated by themselves. Several respondents in the survey highlighted difficulties in

obtaining accessible information to explain contraceptive choice to women they were supporting. If women with learning disabilities are unable to access appropriate information (for example in easy read or multi- media formats) about contraceptive function and choice (Rowlands, 2011), and this is combined with a widely reported lack of access to sex education (CHANGE, 2009; Garbutt, forthcoming) it is perhaps not surprising that women are not raising issues of contraception themselves.

The survey also asked who was involved in choosing the type of contraceptive and who, in the respondent's opinion, made the final decision regarding the type of contraceptive. Once the topic of contraception had been introduced, respondents reported 62% of women with learning disabilities had been involved in discussing whether to use contraception and which type of contraception would be most suitable for them their choice of contraception. 14% of partners were involved in discussions. 38% of respondents said that the women themselves had made the final decision about contraceptive type. GPs were the most significant other final decision makers for 23% of women, and mothers the second most influential for 16% of women.

Several mothers and staff highlighted problems in obtaining accessible information about contraception, to support women with contraceptive choice. For example, one mother commented:

there was no easy read/pictorial format. Further discussion with internet research was completed by myself and a learning disability Occupational Therapist to try to ensure she understood and was making the correct decision.

(Mother of daughter with mild learning disability)

What prompted consideration of contraception?

28% of respondents said that contraception was required because the woman concerned was sexually active. In 15% of cases there was an expectation that the women would become sexually active. Fear of pregnancy was cited in 31% of responses, confirming McCarthy's (2009) finding that contraception is frequently prescribed to women with learning disabilities 'just in case'. In 17% of cases management of menstruation was cited, again this is in line with other research findings (see van Schroyen Lantman-de Valk et al; 2011).

Contraceptive type, reason for usage and review

The survey asked about type of contraceptive used, the reasons for the choice, and how the decision was reviewed. By far the most widely used form of contraception was contraceptive implant, used by 46% of the women. This was followed by the combined (oestrogen and progesterone) contraceptive pill used by 24% and the progesterone only contraceptive pill, used by 7%.

Given the importance of regular reviews of contraceptive use, particularly if long acting contraceptive implants are used, the survey asked about review. 40% of women had used contraception for between 3-15 years yet only 20% reported that contraception was regularly reviewed. Where changes in contraception were made this was most commonly prompted by the woman experiencing side effects rather than planned review or life cycle changes such as menopause.

Findings part 2: Women with high support needs

This section describes responses received in relation to the 21 women described as having severe or PMLD (collectively described as high support needs). Some comparisons are made with responses concerning the remaining 69 women described as having ‘mild’ and ‘moderate’ learning disabilities. However, due to the smaller number of responses in relation to women with high support needs caution must be exercised in generalising more widely from these observations.

In relation to women with high support needs, the highest number of responses were from family members (38%). Apart from one joint response from a mother and father, all family respondents were mothers. Respondents also identified themselves as independent advocates (14%), paid carers or support workers (10%) and ‘other’ including a community team member, community nurse, medical practitioner and an owner and manager of a residential resource.

Who raised the issue of contraception and when?

The issue of contraception was raised at an earlier age with this group, with 38% of respondents reporting that it arose before the age of 16, in comparison to responses concerning women with mild or moderate learning disabilities where (7%) reported that the question of contraception first arose in this age group. For women in ‘severe’ and ‘PMLD’ groups the issue of contraception was most frequently raised by either mothers (29%) or residential support staff

(29%). Other categories included the GP (10%) a medical practitioner (5%) learning disability nurse (5%) and partner (5%). Perhaps reflective of a higher level of impairment in only one case was the issue raised by the woman herself.

What prompted consideration of contraception?

In response to the question ‘what prompted consideration of contraception’ 19% of this group were described as sexually active when contraception was prescribed compared to 41% in mild/moderate group. Management of menstruation was the most common reason for the introduction of contraception with 50% of respondents citing this as a factor compared to 13% amongst women with mild and moderate levels of learning disability. McCarthy’s (2010a) findings show that management of menstruation is frequently given as a reason for prescribing contraception to women with learning disabilities. The responses to this survey suggest that this reason may be particularly common amongst women with higher support needs.

Some respondents provided further information about the kind of difficulties that had preceded a decision to start contraception. This mother explains how contraception was introduced to stop menstruation as a means of limiting other associated health problems affecting her daughter:

Menstruation each fortnight instead of monthly was making life miserable for my daughter as well as being difficult to manage. Decision was made that this was making her anaemic as well as uncomfortable –this decision has carried on into residential care although tried at different times to see if a regular monthly period cycle was established.

This was tried but the twice monthly period returned so we all decided to carry on with a no bleed policy.

(Mother of woman with severe learning disabilities)

In addition to the difficulties presented to her daughter this mother makes reference to menstruation being ‘*difficult to manage*’. A common reason for medical consultation is parental and carer concerns regarding menstrual management and hygiene (Jeffrey et al, 2013). These concerns can be more common amongst carers of young women with decreased mobility, contractures and bladder or bowel incontinence and those labelled as having behavioural difficulties (Dixon et al., 2005; Backeljauw et al., 2004)⁴. Jeffrey et al. suggest that these concerns can become even more pronounced if the young person is in residential care (2013: 106). It may therefore be useful to explore the introduction of contraception on the grounds of menstrual management and hygiene in more detail in any further research.

In relation to the ongoing management of menstruation another mother raised concerns about what would happen when her daughter’s intrauterine coil needed replacing. This had been prescribed when her daughter was under 16 following menstrual problems.

She will not agree to her having a coil fitting when current one wears out because the fitting is too invasive, and I am sure there must be easier ways to control menstruation. Or even give her a chance to learn how to menstruate without the need for intervention.

(Mother of daughter with severe learning disabilities)

⁴ Conditions more commonly associated with women with severe and profound learning disabilities

The issue of responding to menstrual problems, including advice to family and staff and the need for further research to inform best practice guidance are discussed in section 4.

Fear of abuse and risk of pregnancy

Fear of abuse (33%), avoidance of pregnancy risk (19%) and an expectation that the woman would become sexually active (19%) were other reasons cited for women with higher support needs commencing contraception. As in the work of McCarthy (2010) findings suggest the use of 'in case' contraception to be common across this group.

Responses from family carers afford insight into how contraception is seen as a response to the vulnerability of women with more complex disabilities:

As the mother of this young person I would have preferred her to have been sterilised but was told this was against her human rights as a woman. She will never have children or sustain a relationship with a man and is vulnerable to sexual abuse if not supervised.

(Mother of daughter with severe learning disability)

Similarly in answer to the question of what prompted the issue of contraception one mother whose daughter with severe disabilities began contraception when she was under 16 stated:

It was her vulnerability that was the concern

(Mother of daughter with severe disability)

Such responses support concerns expressed by the World Health Organisation (WHO, 2014) that contraception is used to protect people with disabilities from abuse. Findings also raise questions of whether families facing these concerns are able to access advice and support to explore alternatives to the use of contraception. Many women with high support needs experience difficulties in verbal communication and require daily intimate personal care - it is understandable that parents feel anxious about their vulnerability, particularly if they are living away from home. Further research to establish if such concerns are heightened amongst families of women with high support needs and to explore circumstances that precede parental requests for 'protective' contraception would appear to be of value.

Contraceptive type, duration of use and review

The combined pill (38%) and contraceptive implants or injections (38%) were the most common methods of contraception initially prescribed in this group, followed by Intrauterine (IUD) devices used by 10% of women. Other methods reported were sterilisation (5%) and condoms (5%). Responses indicate that once prescribed some women with higher support needs remain on contraception for substantial periods. One mother reported how her daughter with severe learning disabilities began taking the combined oestrogen/progesterone pill before she was sixteen in order to manage menstruation problems; whilst it was reviewed annually she remained on it for over 25 years.

In response to the question of whether changes were made to contraception after the initial decision to use it, responses indicated a higher rate of change (52%) than amongst women with

mild and moderate disabilities. The most common reasons given were side effects (19%). One mother commented that her daughter:

Switched from implant to pill after weight gain and personality changes.

One mother referred specifically to contraceptive review as part of an ongoing plan to manage menstruation. For example:

As a more refined low dosage pill became available this was used instead [combined pill initially prescribed]. As our daughter is not sexually active the pill is used not for contraception but for regulation of menstrual cycle

(Mother of daughter with severe learning disability)

Another response from parents indicated that contraception was stopped after multi-disciplinary team decision-making agreed it was unnecessary:

It was decided by all parties that as she did not wish to have a sexual relationship she did not require further contraception after the effects of the initial injection had worn off

(Parents of daughter with severe learning disability)

This response however raised further questions about how the decision to give a contraceptive injection was made in the first instance, including issues of capacity, consent and contraceptive choice. Capacity and consent are discussed next.

Capacity, consent and contraception

The Mental Capacity Act (2005) had been implemented for five years at the time of the survey. Given the greater degree of impairment in this group it could be anticipated that respondents involved with women with high support needs would report more experience of the Mental Capacity Act framework in relation to the prescription and review of contraception. However when asked if there had been a formal assessment of mental capacity in relation to contraceptive use only 38% reported that they had been involved in a formal assessment of capacity. 38% of women with high support needs were reported to have been involved in discussions concerning their choice of contraception compared to 84% of those with mild and moderate disabilities.

14% of women in this group were described as making final decisions about the use of contraception. Instead final decisions were most often described as made by mothers and GPs. Although some responses related to decisions made prior to implementation of the MCA the reported lack of involvement of women with high support needs raises further questions about the degree to which the Mental Capacity Act is being fully implemented in relation to contraceptive decision-making and subsequent review.

Importantly, some respondents reported success in the involvement of women from this group in making decisions about contraception, as with this community nurse:

the experience this lady had was positive. At all times she was involved in the process and easy read information was provided.

(Community learning disability nurse working with a woman with severe learning disabilities)

However another family expressed concerns about a residential service that had supported their daughter to obtain contraception when she was not sexually active and without their knowledge:

In this particular case contraception was not needed as she herself had not wanted it and felt pushed into it by staff – ‘just in case’. Parents were not consulted by staff before the event, and were told by our daughter that she had been to the doctor's for an injection but did not really understand what it was for. Had she wished to be sexually active the responsible thing would have been for her to have contraception. We would have then taken her to see her GP for advice on the best method for her.

(Parents of daughter with severe learning disability)

Reflecting the service provider perspective, a front line worker highlighted the sensitivity of broaching contraception with parents:

It is a very difficult subject for most people with learning disabilities particularly if they have a more severe disability and they live with parents who tend not to view their disabled son/daughter as having sexual needs.

(support worker)

The following account from a learning disability team member provides insight into the complexity of decision-making when, as this practitioner describes, menstrual problems co-exist with concerns about capacity, self-harm and maintaining an individual's quality of life:

This [the decision to start contraception] was very difficult, as the lady was not able to advocate for herself. Due to her periods her behaviours were preventing her from participating in activities that she loves to be part of. We were worried ...that she may remove the implant, due to some self harming, but in the end she does not pay any attention to the implant in her arm. We were not aware of any contraception best interest procedure, so we used the standard best interest template, but this did take a long time to come to a pathway that was in this ladies best interest. We monitored for several months, of how much of an impact her periods were having on her quality of life. This was not easy.

(Learning Disability team member supporting a woman with severe learning disability)

This team member's reference to 'not being aware of contraception best interest procedure' highlights how practical implementation of legal frameworks such as the MCA in relation to contraceptive decision-making can easily flounder and be subject to delays within practice settings as staff struggle to clarify the appropriate tools and steps to follow. We return to this subject again when we consider the implications of our findings in relation to issues of consent and capacity.

Third party responses provide insight into the complexity of contraceptive decision-making faced by a range of parties engaged in supporting a small sample of women with higher support needs. Several respondents (both parents and professionals) highlighted a wish for further information and advice to support decision-making, echoing findings from McCarthy's sample of GPs (2011).

Discussion

The survey responses presented here are from a small convenience sample. Nonetheless this exploratory research raises some important issues. Significantly it affords further insight into the experiences of those supporting contraceptive decision-making with women with severe and profound disabilities - a group whose experiences remain under reported in the literature. Responses suggest that for these individuals contraception may be prescribed earlier and more frequently in response to menstruation difficulties.

This survey reinforces findings from other research that many women with learning disabilities do not decide to take contraception (McCarthy, 2009a) but have the decision made for them. They take contraception when they are not sexually active, in case they become pregnant; to manage menstruation (Carlson and Wilson, 1994; McCarthy, 2009a); and, disturbingly, to protect against abuse (McCarthy, 2009b; Chou and Lu, 2011; WHO, 2014). They are, as McCarthy also found, more likely to be prescribed long-acting contraceptive implants or injections than the wider population. In this respect the third party survey contributes to an emerging evidence base that contraceptive decision-making is an area where substantial gaps

continue to exist between policy and day-to-day practice. Despite the current legislative and policy framework, these findings reinforce that reproductive control is not an historical institutional problem but very much a ‘contemporary community-based one’ (McCarthy 2009b: 203).

The high use of long acting contraception

The high use of contraception injections or implants reported in this survey echoes findings from previous research (Weiner, 1997; McCarthy, 2009a; McCarthy, 2010a). Rowlands (2011), in her review of mental capacity law and contraceptive decision-making with women with learning disabilities, ranked common contraceptive methods in order of increasing restrictiveness of a person’s rights and freedom of action. As reference to Rowlands’s table indicates, contraceptive methods reported in this survey are more restrictive of individual rights, with greater reliance on methods that are longer acting with more intrusive procedures to begin usage. In advising people with learning disability, their partners and carers, Rowlands highlights that such concerns need to be carefully balanced against the perceived importance of avoiding a planned pregnancy.

Table 1 Adapted from Rowlands, 2011 Methods of contraception in order of a person’s rights and freedom of action			
Method	Discontinuation possible by client	Duration of action	Formal procedure necessary for initiation
Condom	Yes	Transient	NA

Combined pill	Yes	Transient	NA
Progesterone only pill	Yes	Transient	NA
Injectable	Yes	12 weeks (plus potential delay in return of fertility of up to one year)	Yes-but minor
Implant	No	3 years	Yes*
Intrauterine system	No	5 years	Yes*
Intrauterine device	No	10years	Yes*
Sterilisation	No	permanent	Yes*

*In most cases amongst women with learning disabilities require general anaesthesia

Responses reporting lack of accessible communication, lack of involvement in contraceptive choice, low levels of involvement in final decision-making and limited contraception review highlight that more effort needs to be put into enabling women with learning disabilities to exercise as much choice and control as possible. To this end, Rowlands (2011) advises that it is important to consider the role of partners, as in situations where there is a trusting relationship, without power imbalance, a partner with a milder disability may be able to assist in compliance with repetitive medication or in considering contraceptive choice. Heterosexual learning disabled couples (Hreinsdóttir and Grétarsson with Stefánsdóttir, forthcoming; Ledger et al., forthcoming) writing about their experiences of everyday life and decision-making explain how they draw upon each other's strengths to become more independent as a unit. Yet survey respondents

reported that in only 14% of cases were partners involved in contraceptive decision-making, raising this as an issue for practice.

Monk (forthcoming) argues that the fact that sexuality and parenting are complex issues for people with learning disabilities today is in part the legacy of the past. The historical context of reproductive control was discussed earlier in this article. Survey findings suggest that stereotypes of women with learning disabilities as either asexual and child-like or irresponsible and incapable of making decisions about contraception and parenting continue to hold influence. There was very little evidence of people being empowered to realise their rights under disability equality legislation. McCarthy points out that whereas sterilisation is subject to legal oversight no such safeguards exist for the use of long-term contraception:

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. (2010b: 264)

In this respect we argue that the use of long acting contraception with women with learning disabilities should be subject to scrutiny to ensure that best practice is adhered to. Their use means that it is critical that women themselves understand the purpose of the medication and that it will prevent them conceiving.

A need for further support?

Anxieties voiced by respondents suggest contraceptive decision-making, responding to the risk of pregnancy, protection from abuse and the management of menstruation are problematic areas where families and staff would appreciate further information, advice and opportunity to share concerns and good practice. A number of respondents queried if contraception was necessary for their daughters; others raised concerns about a lack of accessible information and advice. Such responses indicate a gap in services for families: an area where proactive support and improved information may bring positive outcomes for women with learning disabilities in terms of 'in case' contraception and reliance on contraception to manage menstruation. Further work to evaluate the advantages of such support would be of benefit.

Women with high support needs, capacity and consent

The survey revealed particularly interesting data concerning women described as having high support needs. The most striking finding here was that these women were likely to be prescribed contraception at an earlier age than the women with less severe impairments, primarily to manage menstruation. For 38% of women with high support needs contraception commenced before the age of 16. Jeffrey et al. (2013) suggest that the Children Act, Family Law Reform Act and Gillick/Fraser guidelines bring about two relevant points in relation to consent and prescription of contraceptives to girls with learning disabilities who are under 16 years. Firstly, that the requirement for interventions should be the least restrictive of basic rights and freedom, and second that those with parental responsibility have the legal right to give consent on behalf of minors for medical treatment. Proxy consent is limited in that a parent cannot insist on treatment that doctors believe is not in the child's best interests. Jeffrey et al (2013) emphasise

that the interests of the child must remain paramount, and acknowledge that this can be difficult to achieve when the parents or carers have their own agenda; for example, parents can request cessation of menstruation because of the effect on their own quality of life, when it may have no impact on the quality of life of the child. McCarthy's GP survey (2010a) highlighted how many doctors frequently looked to parents and staff as 'proxy' decision makers, and particularly for children this is to be anticipated. Findings highlight the value of further research into the use of contraception (and possible alternatives) to address menstruation difficulties and explore decision-making processes, for both children and adults.

As discussed earlier, the MCA introduced a presumption of capacity and a requirement to evidence careful assessment of decision-specific capacity if there are doubts about the person's ability to consent (including evidence that all practicable steps have been undertaken to enable the person to make a decision about contraception without success). The reporting of a low rate of involvement in discussion of contraception amongst women with high support needs is of concern as it is hard to see how their decision-making capacity could have been maximised if they were excluded from the discussion.

The low rate of formal capacity assessments for women with high support needs may also reflect the finding that, as reported earlier, for women with high support needs contraception may be given at a younger age. The Mental Capacity Act (MCA) states that adults who lack decision-specific capacity (using criteria clearly defined in the Act) should be treated in a way that serves their best interests and that, in determining their best interests, decision-makers have a duty to

consult a range of people (Jeffrey et al, 2013). However the MCA does not apply to children under 16 years old.

Menstruation management and contraception

The survey confirmed that management of menstruation is commonly cited as a reason for commencing contraception, with over 50% of respondents citing this as a factor for women with high support needs. Within this group, high usage of contraceptive implant and injections was also reported. Given the often complex health problems frequently experienced by people with higher support needs, one would expect that contraceptive use would be closely monitored in this group of women. The survey was unable to furnish clear evidence that this is the case. Medical literature highlights research into managing the menstrual problems of young women with disabilities is limited and that consequently there is little guidance for best practice (Jeffrey et al., 2013).

Jeffrey et al. (2013) stress that the onset of menstruation can lead to significant distress and deterioration of quality of life for both young women with learning disabilities and their carers. In the light of this, concerns about menstrual management and hygiene are common reasons for parents and staff to seek medical advice, as evidenced by responses in this survey. Jeffrey et al., report how distressing symptoms such as dysmenorrhoea (acute period pain, usually in the pelvic region, of an extent that it interferes with daily activity), menorrhagia (when an excessive amount of blood is lost), increased seizures, cyclical behaviour disturbances and an inability to cope with fluctuating emotional states due to hormonal changes disrupt the lives of women with

learning and physical disabilities. In their review of clinical options for managing menstruation difficulties for adolescents with learning disabilities Jeffrey et al. draw attention to the fact that no research has yet been undertaken into the long term safety of girls who begin taking the combined pill just after starting to menstruate (2013: 107) and highlight that whilst the use of Depot injections to control menstruation may be of value to some young women it should be subject to review by clinicians in view of the risk of diminishing bone density and the substantial risk of weight gain.

Conclusion

It would be hard to escape the conclusion that decisions about contraception for women with learning disabilities are complex, and often messy, and far from the straightforward assumptions about 'rights' to relationships, family life and parenting in *Valuing People Now* (2009) and the UN's CRPD. Although statements of rights are crucial to moving on practice, it is in their enactment day to day that rights will be realised (Johnson and Walmsley, 2010), and here the survey sheds some light. Some recent publications (Tilley et al., 2012; Chapman et al. forthcoming) have proposed continuities between eugenic practices strongly associated with the former hospital movement and more informal 'newgenics' which continue to limit sexual and reproductive lives of many women with learning disabilities today. 'Newgenics' is defined by Malacrida (2013) as including lack of information about sexuality, and the involuntary or not fully informed provision of long-term contraceptives or sterilisation. Answers to the survey from family carers, front line staff and a range of professionals directly involved in contraceptive decision-making with women with learning disabilities suggest that newgenic practices continue,

with decisions made on behalf of women, often motivated by a fear of the consequences of pregnancy.

The findings, when placed alongside existing studies, indicate a pressing need for further research in this area in relation to:

- Application of the MCA and how this impacts on contraceptive decision-making.
- The health implications of long-term use of contraception, particularly given the relatively low life expectancy of women with learning disabilities, reported to be 60 in 2013 (Heslop et al), lower than that of men with learning disabilities. We need to know more about steps that are taken to ensure that contraception is reviewed regularly, given the known deleterious effects of long term use of oral and injected contraceptives.
- The value of improved information and support about menstruation management to families.
- The experiences of women with high support needs - a group often excluded from research (Boxall and Ralph, 2010).

In conclusion we argue that the findings from this survey of third parties involved in contraceptive decision-making, when combined with findings from other studies, highlight serious concerns and substantial gaps between policy and practice. We identify areas where further research is needed. However, it is important to recognise these survey findings also indicated that some, albeit a minority, of women with learning disabilities are making the final decision about their contraceptive choice, that accessible information is being sought out and used in some circumstances and that some staff are aware of the need to follow best interest

decision-making practice when supporting women with higher support needs to make contraceptive choices. The degree of interest and concern expressed across a range of third party respondents is important. A high response rate from families, particularly mothers, involved in supporting their daughters in this area suggests that services may benefit from giving further thought to how local special interest networks of support could be established to share experiences and best practice in this field (Simpson et al 2006; FPA, 2012). As highlighted by recommendations from the CIPOLD review of NHS care for people with learning disabilities, in the field of contraceptive decision-making also there is a need to ‘learn and share what is working well and to shine a light on what is possible, as much as identifying what is wrong’ (2013: 1).

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