#### ORIGINAL PAPER

# Prescribing Contraception to Women with Intellectual Disabilities: General Practitioners' Attitudes and Practices

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**Abstract** The challenges of providing appropriate reproductive healthcare to women with intellectual disabilities are set within the context of a primary health care system. The rationale for this study was to explore the prescribing practices and attitudes of General Practitioner's (GP) when women with intellectual disabilities come to them for contraception. The data reported in this paper come from a cross-sectional postal questionnaire survey conducted with 162 GPs across two counties in England. The majority of respondents had 10 or fewer women with intellectual disabilities of child bearing age on their caseloads. The most commonly prescribed methods of contraception were the Pill (39.7%) and depot medroxyprogesterone acetate (DMPA), (34.2%). The difficulties faced by GPs in determining 'best interests' are explored, as are the issues related to the women's capacity to consent to sex.

**Keywords** Intellectual disabilities · Contraception · Women · England

#### Introduction

#### Background

Providing respectful and appropriate reproductive health care to women with intellectual disabilities has always been a challenge, both within specialist intellectual disability services and in the National Health Service (NHS) more generally. This is for two main reasons. The first relates to shortcomings people with intellectual disabilities so often experience within the primary health care system [1]. Previous research suggests that, despite generally having greater health needs than the non-disabled population [2], people with intellectual disabilities often struggle to get their health needs met; they face negative attitudes from health care providers, communication problems frequently arise and diagnostic overshadowing (physical or psychological symptoms being wrongly attributed to the

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intellectual disability) commonly occurs [3]. Although General Practitioner's (GP) acknowledge that they are responsible for the medical care of people with intellectual disabilities in the community [4] and people with intellectual disabilities have long been recognised as having equal rights of access to good health care provision [5], in practice this often does not happen. Reviews of the literature [6] on primary health care provision to people with intellectual disabilities, and the independent inquiry report *Healthcare For All* [1], suggest communication problems, lack of time for adequate consultations, lack of training and knowledge of GPs to be amongst the main reasons for this.

Reproductive health care for women with intellectual disabilities has also been influenced by prejudicial views about their sexual behavior and parenting capacity. Eugenic based ideas, which manifested themselves in forced sterilizations and institutionalisation with strict segregation of sexes have left a historical legacy [7]. Many myths and prejudices still remain about the basic undesirability of women with intellectual disabilities as mothers [8]. These beliefs have lead to contraception sometimes being given to women with intellectual disabilities in a very 'heavy handed' way [9].

The rationale for this study was to explore the prescribing practices and attitudes of GPs when women with intellectual disabilities come to them for contraception.

#### Methods

The data reported in this paper come from a cross-sectional postal questionnaire survey conducted with 162 GPs across two counties in England. As no previously validated questionnaire was available that was suitable, a questionnaire was designed specifically for this study by the author (see Appendix).

The questions focused on the practitioner's experience of contact with women with intellectual disabilities, aspects of their prescribing practice and understanding of issues considered specific to women with intellectual disabilities.

Initially, 284 questionnaires were sent out to GPs in county X, and 38 completed questionnaires were received, giving a response rate of 13.4%. To address the low return, a second study site was located and subsequently a further 258 questionnaires were sent out to GPs in county Y. Of these, 6 were sent to invalid addresses and 124 were returned, a response rate of 49.2%. The survey in County Y was endorsed by the organisation responsible for Primary Care Education in the area. In addition, more effective follow up procedures were facilitated by collaboration with the local Primary Care Trust.

In addition to data generated by the survey, individual interviews were carried out with 23 women with intellectual disabilities aged 20–51 years and these are reported elsewhere [9, 10].

Data were entered into SPSS v 12.0. After data cleaning, the composition of the X and Y samples was examined using a crosstabulation with chi-squared analysis; slightly more men than women responded in the county X sample (65:59), but this difference was not significant. There was no significant difference found between the composition of the two samples. Therefore the analysis shows responses from both counties together.

The qualitative comments on the survey responses were subjected to a thematic analysis. Similarities and differences between and within, respondents' comments were noted, a system of emergent coding was used and categories of themes and sub-themes were searched for until no more emerged [11].

Ethical approval was gained from a university research ethics committee, as well as those of the relevant health authorities.



#### Results

The majority, 57.9% of the respondents, reported having 10 or fewer women with intellectual disabilities of child bearing age on their current list. Interestingly, over 20% of GPs reported simply not knowing how many women with intellectual disabilities they had on their patient list. (This is despite the fact that *Valuing People* [12] directed that doctors should identify all their patients with intellectual disabilities.) Roughly half of the respondents (52.4%) said they had only ever prescribed contraception to a small number ( $\leq 10$ ) of women with intellectual disabilities. Of those who had prescribed contraception, the vast majority (79.9%) cited prevention of an unwanted pregnancy as the usual reason.

The most commonly prescribed methods of contraception to women with intellectual disabilities were the Pill (39.7%) and depot medroxyprogesterone acetate (DMPA), (34.2%), commonly known as the Depo-Provera<sup>®</sup> injection. The third most commonly cited method was the intrauterine device (IUD) (7.5%).

The overwhelming majority of respondents, 94.1%, said that women with intellectual disabilities were accompanied to consultations by another person. Analysis of their qualitative comments showed that in almost all cases the third person was a carer; either a parent or a professional carer. 93.2% of GPs took a positive view of this, for two main reasons: it helped with communication during the consultation; and it helped with compliance afterwards.

The doctors almost uniformly considered (92.1%) women with intellectual disabilities to have less understanding about their contraceptive choices than women in the general population, with 55.4% of these considering it to be a 'lot less understanding'.

Just over half the doctors (55.8%) reported that the main concerns of women with intellectual disabilities regarding their contraception was ease of use.

The doctors were asked if they used any specialist materials (e.g. easy-to-read booklets, pictures or diagrams of the body, video/audio tapes) to help inform women with intellectual disabilities about their contraceptive choices. Although 60% were unaware of the existence of such materials, 40% of the respondents used materials of some kind. However, it is important to note that in interviews with women with intellectual disabilities [8] none of the women felt they had been given reading material at a level appropriate to their needs, which perhaps suggests a difference in interpretation between what GPs think is 'easy to read' and what actually is easy, or easier, for women with intellectual disabilities.

Two main themes emerged from the qualitative analysis:

#### Reliability of women with intellectual disabilities

The single most common concern cited by GPs was that women with intellectual disabilities may not be reliable users of the Pill (or other methods which rely on the user). This concern led many to choose Depo-Provera<sup>®</sup> instead. Where the Pill was prescribed, many GPs explicitly said they relied on carers to give it to the women.

#### Capacity to consent to treatment

GPs were asked what action they generally took if they felt the woman with intellectual disabilities could not consent to treatment. This question produced more qualitative responses than any other in the survey. By far the most common response was for doctors to say that they would discuss the situation with the carer. The intentions behind these discussions were not always clear; after all, if a woman with intellectual disabilities lacks understanding and cannot consent to treatment, this will be the case even after discussion with her carer. As indicted above, most doctors felt that carers could facilitate



communication between them and their intellectual disabled patients, so it is reasonable to deduce that some doctors would hope that better communication could lead to maximising a woman's chance of being able to consent. However, a sizeable sub-category of responses indicated that some GPs were involving carers with the express purpose of gaining *their* consent to the treatment.

These doctors seem to be unaware that proxy consent has no legal validity in the UK. Many of the GPs suggested the individuals or categories of persons they would seek to involve in discussions about a woman's need for contraception. Only a small minority of the doctors mentioned getting a woman's consent to involve a third party in the discussion and none mentioned a woman's need for, or right to, confidentiality.

When saying what they would do, the following were all named as people the GPs would seek to involve:

Parents/Next of kin/Relative (56)

Guardian/legal guardian/legal representative (15)

Person responsible for woman/responsible adult carer (4)

Person who has power to consent (2)

Care home representative/Key worker/Carer/Support worker (58)

Care manager/Social worker (4)

Advocate (4)

Partner (3)

Friend (8)

Neighbours (1)

(NB. Numbers in brackets refer to frequency each category was cited. Some doctors cited more than more category.)

The list demonstrates a lack of consistency, and one might even say lack of boundaries, when it comes to who GPs think it is appropriate to involve. It is difficult to see how those at the bottom of the list would ever have an appropriate role to play in discussions about a woman's need for contraception.

The code of practice for the Mental Capacity Act 2005 outlines the various levels of support which should be given to individuals to enable them to demonstrate whether they can give consent to treatment. Measures such as tailoring information to the individual, varying the location of consultations, allowing ample time for information to be given and digested and using advocates are all highlighted. Yet most GPs in this study tended to rely predominantly or solely on carers to either assist with communication or provide proxy consent.

The second biggest category of responses regarding capacity to consent was for the GPs to say if a woman could not consent to treatment, then they would prescribe on a 'best interests' basis. This was followed by GPs stating that they would seek advice from colleagues (most commonly consultant gynaecologists, followed by intellectual disability psychiatrists and the more general 'experts in the field'). Only one doctor said s/he would refer to the intellectual disability literature for guidance.

#### Discussion

#### **Determining Best Interests**

Clearly, these are not limited to what would benefit individual women *medically*. Other factors, including their general well being, should be considered. However, it is only



appropriate to take into account that individual's best interests, and not 'the interests of their family, the interests of health professionals, or the interests of other people living with the individual' [13]. Arguably in the case of many girls and women with intellectual disabilities, when it comes to contraceptive decisions, these other competing interests are given consideration. In addition, contraceptive decisions may also be taken partly in the perceived best interests of any hypothetical child who may be born, referred to in the literature as a 'potential person' [14]. This takes the already contested area of the 'rights' of unborn children a stage further into the even more philosophically challenging arena of the 'rights' of unconceived children.

Also carer motivation needs to be born in mind; after all, when it comes to reproduction, a GP is unlikely to know whether a paid carer, a relative or parent, has the woman's best interests in mind. Parents are generally assumed to have the best interests of their children at heart, but parents who do not welcome the thought of a grandchild from their intellectual disabled daughter may find it hard to separate out their own interests from their daughter's. There is no doubt that it can be hard for health care professionals to resist pressure from parents and carers [15]: a number of GPs in this study described parents as 'pushy', 'overprotective', or arriving at surgery having 'made their minds up already'. Busy GPs, in short consultations which do not facilitate full and frank discussions, are faced with the unenviable choice of trying to resist undue pressures from parents and other carers or going along with what they request.

#### Consent to Sex

There are two main considerations here: age; and level of ability. In relation to girls under 16, this research project heard [9, 10] from 4 young women (from a relatively small sample of 23) who started using contraception under the age of 15 (2 were age 12, 1 was 13 and 1 was 14). When parents bring 12, 13, 14 year old girls with intellectual disabilities to doctors for contraception, it is not unreasonable to ask questions about the safety of these children (the age of consent to sexual activity in the UK is, after all, 16). Clearly it is a dilemma for doctors if the girl is presented to them as already sexually active at that age, but early signs of possible sexual interest are part of a normal developmental stage and should not be confused with actual sexual activity. It is reasonable for doctors to share their concerns about a girl's vulnerability, not only to sexual intercourse at such a young age, but also to her long term health. Evidence [16] suggests that once they start contraception at such a young age, girls and women with intellectual disabilities tend to remain on it, with all the possible health consequences associated with that.

In relation to level of ability, in this research relatively few doctors explicitly expressed concerns about the involvement of women with more severe intellectual disabilities in sexual activity. They questioned whether a woman who cannot consent to treatment could consent to sex. It was not clear what the doctors did with those concerns, whether they kept them to themselves or reported them to someone else and if so, whom. The question is certainly a legitimate one. It is well acknowledged, and indeed enshrined in the UK mental capacity legislation (Mental Capacity Act 2005) that people may be able to consent to some things and not others. So it is possible that an individual may be able to consent to sex, but not to a medical treatment. Nevertheless, when girls and women with intellectual disabilities are involved in sexual activity where their consent is questionable at best, then that is of concern and warrants further investigation and supportive action [17]. In two of the examples given by doctors in this study, multiple numbers of non-disabled men were known to be having sex with a woman with intellectual disabilities and this is certainly the



kind of case where contraception, whilst probably needed, is certainly not the only intervention required.

One of the doctors who responded to this survey presented the example of a young woman with such a severe degree of intellectual disability that she could not contribute to the discussion on contraception, much less give consent to treatment. Her level of disability was described as being such that she required a general anaesthetic for minor gynaecological procedures. No mention was made either of her actual need for contraception (her mother was worried that she was 'getting friendly with boys') or of her being able to consent to sex. The woman was fitted with an IUCD whilst having a general anaesthetic for other reasons. The doctor commented that 'the whole thing went very smoothly'. This may be so from a purely medical perspective, but not from a disability rights perspective.

## Disproportionate use of Depo-Provera®

Health care practitioners and others who support women with intellectual disabilities have a responsibility to outline both the advantages and disadvantages of any given method of contraception. The disproportionately high use of Depo-Provera® demonstrated in this research and elsewhere [18, 19], leads one to question whether this is always done in practice. Depo-Provera® is not commonly used by women in the general population, only by some 3% in the UK [20]. Despite its undoubted efficacy, it does not appear to be an attractive 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 intellectual disabilities quite as clearly as they might be. Women with intellectual disabilities and their carers need to be informed about the short term side effects they may experience. But perhaps more importantly they need to be aware of the evidence suggesting that prolonged use of Depo-Provera® is associated with low bone mineral density and increased fractures [21]. This is especially true when Depo-Provera® is given from a young age:

Women with DD [developmental disabilities] are likely to begin DMPA at a young age, often near menarche, and to continue its use over a long period of time without opportunity for recovery of bone loss. Decrease in bone mass during adolescence is of particular concern because adolescents are normally gaining bone density during these years. Losses at this time likely affect bone mass, thus increasing fracture risk later in life [16].

#### Limitations of the Study

Certain limitations need to be taken into account in this study. The questionnaire allowed for only a limited number of questions to be asked of GPs and there was no possibility of asking follow-up questions or probing for more information, as would have been the case with interviews or focus groups. Another limitation is, as mentioned earlier, the lack of an existing valid tool for this study, which necessitated use of a new questionnaire.

There was a low response rate at one of the study sites and it is not possible to speculate whether those who did not respond would have differed significantly from those who did, but that is a possibility. Those who responded to the survey are likely to have had a particular interest in intellectual disability and this may have introduced some response bias [22].



#### Recommendations

#### Joint Working

Much of the literature on primary health care for people with intellectual disabilities, and this research is no exception, highlights deficits in those services and therefore some implied criticism of GPs. However, given that a number of health and social care professionals may be involved in the decisions about contraception for women with intellectual disabilities, this points to a need for training and support more broadly. Previous research suggests that when GPs work in a co-ordinated way with other professionals this leads to better quality health care for patients with disabilities [23].

As stated earlier, the GPs in this study had very little experience in prescribing contraception to women with intellectual disabilities. A possible solution to this lack of expertise is to make active links with those who are experienced and skilled in working with people with intellectual disabilities and community nurses are the obvious choice [24]. Whether community intellectual disability nurses fulfil the role of health facilitators for individuals or have more consultative role within the GP practice as a whole, both strategies would seem like an improvement on the current situation. The importance of the role of community intellectual disability nurse in enabling women with intellectual disabilities to seek, and receive, other forms of reproductive health care (e.g. breast and cervical screening) is established in the literature [25, 26]

#### **Enabling Patient Choice and Control**

As with so many other areas of the lives of people with intellectual disabilities, a balance needs to be found between protection and empowerment [27]. For many years certain methods of contraception have been given to women with intellectual disabilities precisely because they require little or no "active user participation" and this has, in the past, been seen as a good thing [28]. Whilst it may still be appropriate for some women with intellectual disabilities, there is a need to challenge such practices on a collective level and emphasise the need for women with intellectual disabilities to be enabled 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. Undoubtedly, the decision to take contraception can be a complex one and any woman needs to weigh up the pros and cons. By definition women with intellectual disabilities are at a disadvantage in this process compared to their non-disabled peers. Therefore, efforts need to be made to educate them as far as is reasonably possible and facilitate a process whereby they can perhaps make a series of short visits to either to family planning clinics or their GP. Information needs to be given in an accessible format [29, 30] and the women need to be able to take it away, consider it with support (e.g. from a health facilitator) and where possible, make their own decisions. Where it is not possible for women to make their own choices, decisions will need to be made then, as now, i.e. effectively without the woman's informed consent and on a 'best interests' basis. But ideally this should always be judged on an individual basis and be the end of a thorough enabling process.

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Conflict of Interests None.



# Appendix

Doctors' questionnaire				
Contraception and women with	learning disabilities			
1. Approximately how many women with learning disabilities		☐ 1- 10		
of child-bearing age do you have on your caseload?		□ 11-20		
		□ 21+		
		☐ Don't know		
2. Approximately how many wo	omen with learning disabilities			
have you ever prescribed contraception to?				
3. What is the usual reason?	☐ To prevent unwanted pre	egnancy		
	☐ To help regulate menstru	uation		
	☐ Other (please			
specify)				
4. What is the most common these women?	form of contraception you prescr	ribe / recommend to		
these women:				
□ Pill	☐ Condoms			
☐ Depo –Provera Injection	☐ Morning After Pill			
□ IUD	☐ Sterilization			
☐ Cap/ Diaphragm	☐ Other (please specify)			
☐ Implant				
5. Do women with learning dis	sabilities generally come to see y	ou?		
Alone				
□w	ith a carer			
☐ With a partner / friend /				
advo	cate			



6. If they come with someone else, what effect do	oes this generally have on the
consultation?	☐ Generally helps
	_
	Generally has no effect
	Generally has no effect
Please elaborate if you can	
7. In your experience, compared to most other won	nen in the general population, how
do women with learning disabilities generally under	erstand their contraceptive choices:
(please underline)	
Same understanding - a little less - a lot less	<ul> <li>no understanding at all</li> </ul>
8. What kinds of concerns do women with learning	disabilities generally have about
contraception?	oncerns about ease of use
□ Co	oncerns about reliability of method
☐ Co	oncerns about side effects
Oti	her (Please specify)
9. If you feel a woman with learning disabilities is	not able to understand fully and
cannot consent to treatment, what action do you tal	ke?
10. Do you have any particular concerns about wor	men with learning disabilities'
ability to use contraception reliably? Please	
specify:	



11. Do you use any specialist materials to help	☐ Easy –to-read booklets
explain contraception to these women?	☐ Pictures / diagrams of body
(please tick all that apply)	☐ Video / audio tapes
	☐ Not aware of such materials
12. If there is anything else you would like to say	about contraception and women
with learning disabilities, please use the next page	. If you have any examples of how a
particular woman with learning disabilities has or	r hasn't been properly supported to
choose and use contraception, I would be interested	ed to hear about it.
Further Comments:	
Thank you very much for taking the time to answ	er these questions. What you have
said will be very helpful for this research project.	
[Researcher's name and address here]	
If you would like details of the outcome of this re	esearch project, please complete the
tear-off slip below. To maintain anonymity of the	research questionnaires, please
return the tear-off slip separately in the small env	elope provided.
I would like details of the findings of this research	h project:
Name:	
Address:	

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