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LEGAL OPINION

Learning disability and contraceptive decision-making

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Key message points

- The Mental Capacity Act 2005 has formalised existing case law and added new requirements in respect of decision-making by people aged 16 and over
- A person must be presumed to be competent unless it is demonstrated otherwise. Competence relates to a specific decision and not to all decisions
- The Court of Protection deals with serious decisions affecting personal welfare matters, including health
- The Court of Protection may appoint a Deputy to act on behalf of the person who lacks capacity
- If sterilisation or abortion are being considered as possible options for a person who is considered to lack capacity, and the person has no-one else to support or represent them, an Independent Mental Capacity Advocate must be appointed
- When assessing a person's capacity to make decisions about contraception, the court will not take into consideration the individual's understanding of what caring for a child involves

Cases

Case 1. Ms A is aged 29. She has moderate learning disability. She has had two previous pregnancies after unsatisfactory relationships with different men and both infants were removed at birth after detailed social work assessments. Two years ago, Ms A married a man with milder learning disability. Since the marriage, there have been reports of obstruction of Ms A's attendance at college and lack of cooperation with her medical and social care by the husband. There are also some reports of domestic violence. It appears that the husband is keen on having a family. The husband dominates the relationship. Ms A had previously accepted depot contraceptive injections but did not continue these because of side effects. She has declined to restart the injections without the husband's knowledge.

Case 2. Ms B is aged 36. She has moderate to severe learning disability. She has been co-habiting with a man who is sometimes violent towards her for the last 12 years. She is dependent on him and her support worker for her care and welfare. The couple have three children. At times these children have lived within the family unit; currently they are all fostered due to varying degrees of neglect. Her partner demonstrates a lack of motivation to use contraception and even prevents health professionals from providing supplies or discontinues the method. Since the birth of her last child, Ms B has consistently expressed a wish not to have any more children. Three years ago Ms B had a subdermal contraceptive implant inserted under general anaesthesia. She is due for a removal/refit procedure but both she and her partner are resisting having the procedure done.

Introduction

There have been big changes in the law relating to adults who lack capacity to give consent in recent years. Most textbooks are now out of date on this subject. Most readers will likely have undergone local training on the Mental Capacity Act 2005 (MCA), but this may well have been rather general. It is therefore considered timely for an up to date assessment of the law in this area. This article is not a complete evaluation of the MCA; it does not cover aspects of fluctuating capacity, lasting power of attorney and advance decisions. Its purpose is to raise awareness on this subject in those working in community sexual and reproductive healthcare in their everyday practice. The article focuses on women with learning disability.

Learning disability

Learning disability consists of a significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently and a lasting effect on development¹. The condition starts before adulthood and is a permanent disability. In terms of cognitive function, adults with learning disability will score lower than two standard deviations below the mean on a validated test of general cognitive functioning². Learning disability exists in a spectrum from mild and moderate through to severe and profound. Learning disability does not include less disabling problems encompassed by the term learning difficulties, such as dyslexia.

Human rights

Women with learning disability have the same human rights as those with normal intellectual ability. The following are excerpts from five of the ten internationally agreed sexual rights³ that are particularly relevant to this subject:

Article 3. All persons have the right to be free from violence, including all forms of physical, verbal, psychological or economic abuse, sexual harassment or sexual violence, rape and any other forms of coerced sex within or outside marriage

Article 4. All persons have the right not to be subjected to arbitrary interference with their privacy, family, home, papers or correspondence and the right to privacy which is essential to the exercise of sexual autonomy.

Article 5. All persons have the right to be recognized before the law and to sexual freedom, which encompasses the opportunity for individuals to have control and decide freely on matters related to sexuality, to choose their sexual partners ...

Article 8. All persons shall have access to community-, school-, and health service provider-based information regarding sexuality in understandable language, including on the means to ensure sexual and reproductive health and decision-making on when, how, and with whom to have sex and when sexual behavior will become reproductive

Article 9. All persons have the right to choose whether or not to marry, whether or not to found and plan a family, when to have children and to decide the number and spacing of their children freely and responsibly ...

Conflicts arise with the sexual partner of the woman with learning disability if there is lack of respect for autonomy, coercion or violence. Conflicts arise with children born to a woman with learning disability in the event of parental neglect or abuse; children's law entitles a child to safety and protection from harm, if necessary invoking safeguarding procedures⁴ and fostering.

An increasing number of people with learning disability are having children⁵. Parental IQ is not itself a predictor of parenting performance, but many parents with a learning disability lose their parenting rights.

Contraception for people with learning disability

Community contraception services have for many years assisted those with learning disability and other vulnerable adults. Many of these services have developed domiciliary or outreach services, so that these clients do not necessarily have to attend clinics. However, there is a paucity of written documentation on how best these services should be run⁶. Despite this, a majority of contraceptive consultations take place in general practice. Few women with learning disability know about community contraception clinic services which is regrettable as staff have more time for consultations and adequate time is crucial for maximising decision-making capacities⁷.

It is important not to make the choice of contraception for the woman, but to allow her the time to make her own choice. The available options are the same as for anyone else⁸. The woman will need accessible information about contraception⁹, not the standard **fpa** leaflets, which need a reading age of at least 10 years. Some women with learning disability can learn to be reliable pill-takers. However, experience of contraceptive use by teenagers with learning disability showed pills to have the lowest satisfaction rating, according to their mothers¹⁰. GPs express concern that women with learning disabilities would not be reliable users of the pill¹¹.

Many women with learning disability feel they do not have the opportunity to make their own decisions⁷; this applies to starting contraceptive use, duration of use and deciding to discontinue. These women often feel decisions are imposed by others.

It is important to consider the sexual partner of the client. Often, those with learning disability meet others with learning disability through their joint accommodation or the centres they attend. It may be that the partner with the milder disability can assist the other in adherence to any repetitive action needed. Apart from in those with the most mild forms of learning disability, the concept of time will be absent; support will be needed or long-acting reversible contraception (LARC) used to avoid the need for adherence. Where there is a trusting relationship without power imbalance, the partner should be involved as much as possible in any education and instruction.

With contraception, as with other areas of life for people with learning disability, a balance needs to be found between protection and empowerment⁷. LARC methods may be appropriate for some, but effort needs to be put into enabling women with learning disability to exercise as much choice and control as possible.

Sterilisation should only be considered for those women with learning disability who are physically capable of procreation and are likely to engage in sexual activity and that there is a real risk of pregnancy¹². Sterilisation would not appear to be justifiable on the following grounds¹²:

- risk of being sexually abused (rather, she needs protection from abuse)
- risk of being traumatised by the experience of pregnancy and childbirth
- lack of parenting ability

A population-based study in Belgium has shown a higher prevalence of sterilisation amongst women with learning disability than in the general population¹³. It would be expected that sterilisation would nowadays be becoming less common in women with learning disability, as it is in those in the general population¹⁴, with greater availability of reversible alternatives.

Mental capacity

Mental capacity is the ability to make a decision. The essence of the test of mental capacity is whether the person concerned enjoys the necessary understanding to embark on the particular enterprise in question¹⁵. A person is unable to make a decision if they cannot do one or more of the following:

- understand the information given to them that is relevant to the decision
- retain that information long enough to be able to make the decision
- use or weigh up the information as part of the decision-making process
- communicate their decision – this could be by talking or using sign language

A person who is deemed to have capacity to consent is termed competent in legal jargon. A person who lacks capacity is termed incompetent.

A person who lacks capacity is defined as a person who does not have the capacity to make a particular decision or to take a particular action for themselves at the time the decision or action needs to be taken. An individual's ability to make decisions is governed by the Mental Capacity Act 2005 in England and Wales, the Adults with Incapacity (Scotland) Act 2000 in Scotland and in Northern Ireland there is currently no primary legislation. This article is written from England and so details will be given of relevant English law.

Decision-making by incompetent adults

Until the MCA became fully effective in October 2007, decision making by incompetent adults was governed by case law¹⁶; the MCA largely incorporates previous case law principles¹⁵. The Act only applies to those aged 16 and over. The Act makes it clear that a person should be presumed to be competent unless it is demonstrated otherwise. The Act also specifies that competence is decision-specific. For instance, a person may be thought to be competent to make a decision about spending money on some furniture, but not to consent to a medical procedure. There are some actions enshrined in law that cannot be consented to on behalf of an incompetent person: these include sexual intercourse, marriage, divorce and placing a child for adoption¹⁷.

Essential procedures to be followed

Decisions must be made on what is in that person's best interests. The care provider must, so far as reasonably practical, permit and encourage the person to participate, or to improve their ability to participate, as fully as possible in any act done for them and any decision affecting them. The information relevant to the decision includes information about the reasonably foreseeable consequences of a) deciding one way or the other or b) failing to make the decision. Those supporting a person who may lack capacity should not use excessive persuasion or undue pressure. Professionals must consider the views of, amongst others, anyone engaged in caring for the person or interested in their welfare.

When considering the decision about to be made, regard must be given as to whether there is an alternative option that promotes the person's best interests which would be less restrictive of the person's rights and freedom of action. This originates from cases such as *SL v SL* in which it was held in the Court of Appeal that insertion of an intrauterine system would be a more appropriate intervention than sterilisation or hysterectomy in a 29-year old with severe learning disability and heavy menstrual bleeding whose mother was concerned that she might become pregnant¹⁸. In a more recent case, P's mother wanted P to be sterilised when her second child was delivered by Caesarean section¹⁹. However, the judge did not have enough evidence at hand for the court to make a decision on P's competence and best interests and so the Caesarean went ahead without concurrent sterilisation. Table 1 shows contraceptive methods ranked in order of increasing restrictiveness.

The views of family members may be taken into account as long as it appears they have the person's best interests at heart. Under the MCA a person is not to be treated as unable to make a decision merely because it is an unwise decision.

Restraint of a person who lacks capacity is only permitted if the person using it reasonably believes it is necessary to prevent harm to the person concerned. The restraint used must be a proportionate response to the likelihood and seriousness of the harm.

For people with learning disability, the way that information is presented to them may need to be as simplified language or by the use of visual aids such as pictures, objects or electronic media²⁰. Communication needs to be at a slow pace and may have to be repeated. Support during this process may be needed from a person they are familiar with or an interpreter.

Serious medical treatment

The MCA created the role of Independent Mental Capacity Advocates (IMCAs) to be appointed by NHS health trusts. Under section 37 of the MCA, if it is proposed to provide “serious medical treatment” then, for those who have no-one else to support them (other than paid staff), an IMCA must be appointed to represent the person, unless the treatment is required urgently. Serious medical treatment is defined in secondary legislation²¹ as treatment which involves providing, withdrawing or withholding treatment in circumstances where

- a single treatment is being proposed and there is a fine balance between its benefits to the patient and the burdens and risks it is likely to entail for them
- there is a choice of treatments and a decision as to which one to use is finely balanced
- what is proposed would be likely to involve serious consequences for the patient

Serious medical treatment is considered to include sterilisation and abortion¹⁷. IMCAs have the right to see relevant medical records.

In practice, most people with learning disability will have family members or friends who take an interest in their welfare and through them will receive support and representation. But IMCAs will act as a safeguard for those who do not.

Code of practice

Detailed guidance on mental capacity can be found in the Code of Practice¹⁷; the MCA imposes a duty on health professionals to have regard to the Code of Practice. The Code of Practice is not law, but carers and professionals are expected to give good reasons why they have departed from it. A failure to comply with the Code has no sanctions attached to it, but it can be used in evidence in a court. Health professionals are required to demonstrate in their record-keeping that any decision made has been based on all available evidence and has taken into account any conflicting views²². The following need to be recorded:

- how the decision about the person's best interests was reached
- what the reasons for reaching the decision were
- who was consulted to help work out best interests
- what particular factors were taken into account

Best interests meetings

A formal best interests meeting may be required to decide upon and plan actions needed where the issues facing a particular client are complex. The procedure and recording of what took place in the meeting must be able to withstand subsequent scrutiny by regulatory bodies or the Court of Protection.

The Court of Protection

From 2007, the Court of Protection has had wider powers under the MCA. The Court of Protection deals with serious decisions affecting personal welfare matters, including health, previously dealt with by the High Court¹⁷. The court is invariably involved when there are potentially conflicting concerns on behalf of Social Services, the person with learning disability and the partner of this individual. Social Services has a responsibility to protect the individual from harm in the form of abuse, unwanted sexual intercourse and unwanted pregnancy. Social Services must also protect any children born. The individual and her partner need to have their human rights and autonomy respected.

Circumstances in which the Court would expect to be consulted include cases involving the proposed sterilisation of a person who lacks the capacity to consent to this and all other cases where there is a doubt or dispute about whether a particular treatment will be in a person's best interests. Neither sterilisation incidental to the management of the detrimental effects of menstruation nor abortion need automatically be referred to court if

there is no doubt that this is the most appropriate therapeutic response²². For instance, a woman who is chronically anaemic from large fibroids which have not been amenable to less radical measures could have a hysterectomy without a court hearing.

An application can be made to the court in respect of any person who lacks capacity. The duty officer of the Official Solicitor will advise on the appropriate procedure (<http://www.courtfunds.gov.uk/os/adult.htm>). The court can make a ruling as to the lawfulness of any act concerning the individual.

Even though the MCA has subsumed relevant case law, the Court of Protection can develop its own case law. In the first case of its kind, the court was asked to consider whether a young married woman lacked capacity to decide whether to use contraception and whether it would be in her best interests to be required to receive it²³. A local authority applied to the Court of Protection seeking declarations that Ms A lacked capacity to decide whether to use contraception and that it would be in her interests for her to be required to receive it. The local authority submitted that Ms A would need to understand the reasonably foreseeable consequences of the decision; this would include, if the decision was not to use contraception, what would be involved in caring for a child. The Official Solicitor, on behalf of Ms A, submitted that that would “set the bar too high” and would deny capacity to large numbers of women who would currently be regarded as having capacity in relation to contraception. The judge, Mr Justice Bodey, came up with a new test for capacity to decide on contraception. He stated that the test would need “to be applied daily in surgeries and family planning clinics, during appointments lasting perhaps less than half an hour”.

The judgment was that allowing the use of a wide test which included the social consequences of not using contraception would blur the line between capacity and best interests. It would invoke considerations of whether Ms A could bring up a child which might then tempt her advisers and carers into treating a decision not to use contraception as unwise, and so not in her best interests. The judge ruled that her understanding of what bringing up a child would entail or the likelihood of the child being removed from her care should not be included in the test. To apply the wider test “would risk a move away from personal autonomy in the direction of social engineering”. The test should include only the immediate medical issues surrounding contraception including:

- the reason for contraception and what it does (which includes the likelihood of pregnancy if it is not in use during sexual intercourse)
- the types available and how each is used
- the advantages and disadvantages of each type
- the possible side effects of each and how they can be dealt with
- how easily each type can be changed
- the generally accepted effectiveness of each

When the judge applied the proposed test to this case, he found that Ms A lacked capacity to decide whether or not to use contraception. This was because of the presence of coercive pressure from her husband, both intentional and subconscious. Because there was ongoing work with professionals taking place, the judge made no order at that time about best interests. If this case comes back to court, it will be interesting to see a judgment on the second part of the local authority's application. So far, there is no case law on whether and in what circumstances a woman can be forced to use contraception.

Court-appointed deputies

Sometimes, the Court of Protection will not make a single judgment but will appoint a person to act for and make decisions for the person who lacks capacity¹⁷. This person may be a family member, a friend, a professional working in the local authority or a solicitor. Deputies must act in accordance with the Code of Practice.

Discussion of cases

Case 1

Case 1 is the Court of Protection case mentioned above. The history clearly demonstrates Ms A's vulnerability and her inability to fend off the advances of various men. She was consistently assessed as being unable to care for both of her infants when living alone. Now, in a stable relationship, she is receiving the benefit of support from her husband who has greater intellectual ability than she has. Nevertheless, she is also being exploited and abused by her husband. She is dominated by him and is disadvantaged in the joint decisions they make together. She tends to defer to him and fears retribution if she disagrees with him. It is not clear how much she wants another baby, or how much this is her husband's wish. It is interesting that she is judged by the court as lacking capacity to make a decision about use of contraception, not because of her inherent learning disability, but because of an emotional reaction to pressure from her husband. One tends to think of intellectual function in learning disability as constant, but this case demonstrates that this may not always be so.

Case 2

The situation in Case 2 is very different in that Ms B has experienced children living in the family home and does not want further children. Also, she is much less independent than Ms A. She needs daily support from social services. She is incapable of looking after herself, let alone any children. Her partner does not look after the children either. There is the continuing thread of domestic violence too. Ms B has a complete lack of understanding of the concept of contraception as well as an inability to use it.

Ms B clearly lacks capacity to make decisions about contraception for herself. Her partner is obstructive and uncooperative with health and social care professionals. The Court of Protection would need to make a judgment about Ms B's best interests. Would it be justifiable for her to receive injections with restraint? In the likely event that she could not tolerate or cooperate with a procedure such as implant insertion or intrauterine device/system insertion, would general anaesthesia be justifiable? How would more minor procedures needing to be repeated be compared to female sterilisation in terms of risks and benefits? Female sterilisation is inherently more risky but is a "one-off" procedure.

Conclusions

Since the MCA came into force, there have been many referrals of difficult cases to the Court of Protection. Some of these have been high-profile, attracting media coverage. These court cases deliberate on the woman's capacity and best interests in great detail. The court has demonstrated that it will not be bounced into fast track decisions, for instance when a woman is scheduled for a Caesarean section, and that the parents of the woman do not always get the decision they are asking for. In a significant shift in public policy, the court is now extremely reluctant to order that a sterilisation be performed.

Assisting people who lack capacity to make health-related decisions is complex and time-consuming. The law dictates that certain procedures are gone through with any individual before decisions are made about contraceptive options. Multidisciplinary work is needed between social worker, member of the Community Learning Disability Team, GP and specialist in community sexual and reproductive health care. In specific circumstances, the case must be placed before the Court of Protection for a ruling. The best interests of the person with learning disability are always paramount.

All this is challenging for the health and social care professionals concerned who will be involved in lengthy attendance at meetings, report writing and possibly attending court. Those with learning disability invariably receive legal aid for their case to be heard (www.legalservices.gov.uk/about_legal_aid.asp). Some cases are heard over several days and with more than one hearing. The health service is undergoing reorganisation and is subject to national financial strictures. Nevertheless, there is a legal obligation to contribute to decisions about an individual's capacity and best interests.

Author's note

The Mental Capacity Act 2005 can be accessed at www.legislation.gov.uk.

Table 1 Methods of contraception in order of increasing restrictiveness of a person's rights and freedom of action

Method	Discontinuation possible by client	Potential hormonal side effects	Effect on menstruation	Duration of action	Formal procedure necessary for initiation**	Risks of procedure	Further procedures needed for continuation**
Condom	Yes	No	None	Transient	No	N/A	N/A
Pill	Yes	Yes	Improved	Transient	No	N/A	N/A
Injectable	Yes	Yes	Usually periods abolished	12 weeks*	No – transient discomfort from needle	N/A	N/A
Implant	No	Yes	Often induces problematic bleeding	3 years	Yes	Minor	Yes
IUS	No	(Yes)***	Usually periods abolished	5 years	Yes	Minor	Yes
IUD	No	No	May make worse	10 years	Yes	Minor	Yes
Sterilisation	No	No	None	Permanent	Yes	Major	No

*Plus delay in return of fertility of up to one year

**In all but mild cases of learning disability this will almost certainly necessitate general anaesthesia

***Usually mild and initially only

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