THE STERILISATION OF WOMEN WITH LEARNING DISABILITIES - SOME POINTS FOR CONSIDERATION

Introduction

The sterilisation of people with learning disabilities was a procedure that took place with disturbing frequency during the first four decades of the 20th century (Park and Radford, 1998). This was largely associated with the Eugenics movement, in the mistaken belief that eliminating the opportunities of people with learning disabilities to reproduce would eliminate the incidence of learning disability in the general population. Indeed, as late as 1976 in Sweden, the practice continued, as the behaviour of women with learning disabilities was regarded as “unacceptable” (Denekens et al., 1999). In Germany by 1937, an estimated 225,000 people with mental illness or learning disability had been sterilised (Spann, 1975).

Increased research into learning disabilities undermined the false belief that all forms of learning disability were heritable. This new understanding, in combination with movements such as “normalisation” (Wolfensberger, 1972) and The Human Rights Act (1998) has confirmed the rights of people with learning disability to refuse sterilisation procedures. However, this refusal still relies upon the assessed capacity of someone with a learning disability to consent.

This paper argues that consent to sterilisation should be viewed individually, with specific parameters to consider, but within the context of the standard capacity to consent literature. It is important that a more individualised procedure for assessing consent to sterilisation is developed and a model for such is proposed. The reason for this individualised approach is due to the complex nature of consent to this particular procedure and the major and irreversible consequences it may have upon someone’s life.

The complex task of obtaining informed consent to sterilisation from somebody with a learning disability and assessing the appropriacy of sterilisation, has often fallen to the surgeon, the G.P. or ultimately, if there is a question about the individual’s capacity, the Court. The Court will want to establish whether or not the proposed sterilisation is in the best interests of the patient. The Judge will require to be satisfied that those proposing sterilisation are seeking it in good faith and that their paramount concern is for “the best interests of the patient, rather than their own or the public’s convenience” (Gunn, 1996 p. 60). In order to assess this proposition, the court is likely to ask for expert support in assessing these questions:

1) Is the patient unable to make her own decision and is she unlikely to develop sufficiently to make an informed decision about sterilisation in the foreseeable future?
2) Is there a real need for contraception because:
   - the person is physically capable of procreation; and,
   - the person is likely to engage in sexual activity; and,
   - there is a real danger of pregnancy, not merely a chance.
3) Is the patient likely to suffer trauma should she experience that which sterilisation aims to prevent and this trauma is less than that of pregnancy?
4) Is the patient permanently incapable of
caring for a child?
5) Is there no less intrusive alternative?
6) Is sterilisation necessary at the time of the application (Gunn, 1996)?

This article aims to support this process, using the knowledge gained about people with learning disabilities through psychological research. It describes a process of assessment for consent to sterilisation for someone with a learning disability and key areas that require consideration. It is not intended to be either prescriptive or exhaustive, emphasising the importance of assessing each case on an individual basis.

Consent

It is important to recognise that an individual with capacity is entitled to make his/her life decisions on his/her own behalf. However, as an individual's capacity diminishes and the risks associated with his/her actions increase, it is increasingly necessary, due to legislation (Lord Chancellor's Department, 1997; Lord Chancellor's Department, 1999), to ensure safeguards exist to protect the individual's right to autonomy and individual safety.

In establishing capacity to consent, there is a constant dilemma of gaining a balance between a person's right to self-determination in making important life decisions (Dye et al., 2003) and duty of care to protect vulnerable people from exploitation and harm. In terms of consent, there appear to be three main components (Morris et al., 1993, as cited by Dye et al., 2003; Arscott, 1997).

1) Possessing sufficient information relevant to the decision to be made.
2) Having the capacity to make a decision and to understand its consequences.
3) Making the decision voluntarily, free from coercion.

Assessing somebody with a learning disability in terms of his/her capacity to consent can be an extremely complex process. A number of barriers exist here.

Acquiescence

Due to cognitive factors and the less powerful position in society people with learning disabilities tend to have (Atkinson, 1989), it does not seem surprising that research has demonstrated a greater tendency for people with learning disabilities to acquiesce compared to the general population (Rosen et al., 1974).

Communication

Communication difficulties are often associated with learning disabilities, posing problems in terms of both comprehending consent and being able to give informed consent (Sigelman and Budd, 1986).

Disempowerment

Whilst the Human Rights Act (1998) and movements such as Normalisation (Wolfensberger, 1972) attempt to empower people with learning disabilities, important life decisions for people with learning disabilities are often made by others. This may undermine their ability to both make and practice making their own decisions (Brechin and Swain, 1989).

These factors have led to establishing some important areas to bear in mind when interviewing/assessing the capacity to consent of people with a learning disability.

The assessment procedure should ensure consideration of: use of appropriate communication, e.g. visual/simple sentences; type of questioning used; avoiding acquiescence factors, e.g. through using open questions or breaking questions down into small parts to extract closed and specific answers (Biklen and Moseley, 1988); avoiding leading questions; ensuring that the client feels comfortable in the
setting in that his/her knowledge is explored (Atkinson, 1989); and ensuring that the person assessing the client is someone that the client feels comfortable with and is independent of the decision.

The evaluation process should look at: whether this is a clear decision with reasoning behind it; how long it has taken for the client to reach this decision; if there are any changes likely in his/her mental state in the future that may effect this decision; the socio-cultural influences on this decision; the influences of “significant others” (i.e. those people who have relatively important relationships with the client and therefore may have more influence, such as parents or partners) on the client and the client’s understanding of his/her rights?

Consent to sterilisation

When considering the issue of sterilisation, there are further issues, which may complicate assessing the consent of someone with a learning disability to this procedure.

Emotional Intelligence

Choosing sterilisation has proven to be a very emotional decision for people (Haws et al., 1997). Whilst some valid measure of cognitive intelligence exist, there are few valid measures of emotional intelligence.

Parental/Carers Coercion

In a survey of parents of a child with learning disabilities, 53% of respondents indicated that they would like their child with a learning disability to be sterilised (Bambrick and Roberts, 1991). As the research points to people with learning disabilities being vulnerable to coercion, this poses a risk. When we look at recent case law (Howard, 2000) it is evident that a significant number of applications for sterilisation have been initiated by parents. [R-B (A Patient) v The Official Solicitor sub nom Re A (Mental Patient: Sterlisation), 1999] A cause for concern may be the parents’ negative view of their child engaging in sexual activity provoking this insistence on sterilisation.

Cognitive Understanding

The understanding that you will never have a child if you undergo sterilisation may be difficult to grasp. In particular, the concepts of pregnancy and parenthood are quite abstract if they have never been experienced previously. A true understanding of the emotional implications of sterilisation is extremely difficult to establish. A number of women without learning disabilities have reported subsequent regret following sterilisation due to a change in perspective, e.g. having a new partner. It is likely that with cognitive limitations, the idea that your perspectives or wishes might change in the future is extremely difficult to understand (Ramanathan, 2000). Furthermore, weighing up different risks, e.g. the risk of anesthesia/future emotional risks/pregnancy/current health risks is another complex cognitive task.

Gillon (1987) makes the point that if the person with learning disabilities is unlikely to develop sufficiently to parent a child then he/she is not actually forfeiting any realistic chance of parenthood anyway. However, this seems to move away from choices regarding sterilisation to questions around the right to parent.

Communication Difficulties

Research suggests that counselling is an important part of the sterilisation process (Ramanathan, 2000). Communication difficulties may interfere with this process to some degree, however, this is not to say that it is not possible (Sinason, 1989).
Assessment of the issue of sterilisation

Assessing someone’s understanding of sterilisation is vital to this process. The important points for consideration are: understanding of health risks, permanency; mental health risks; ability to learn about aspects that may not be currently understood; assessment of emotional intelligence; understanding of pregnancy/motherhood; the influence of others on this decision; and comparison of health risks and health benefits of sterilisation.

The Issue of Pregnancy

In a number of court cases it was argued that sterilisation of somebody with a learning disability was necessary because of the risks associated with them becoming pregnant. However, in some cases, it seems that the actual risks of pregnancy are minimal. In one case, a mother expressed concerns about pregnancy not because her daughter was sexually active but because she was moving to a care home, and she feared that her daughter might be sexually abused [Re LC (Medical Treatment: Sterilisation), 1997]. It seems that this woman should be protected from sexual abuse, rather than from pregnancy.

“As a society we would not complacently accept ‘normal’ girls and women being subjected to non-therapeutic sterilisation because they had mood swings, period pains, irregular, heavy or ongoing periods or because there was a possibility of them being raped, yet this form of ‘control’ is tolerated if the woman or child has an intellectual disability” (Spicer, 1999).

Whilst the risk of being sexually abused is heightened if somebody has a learning disability (Furey, 1994), this should be a separate issue to be tackled. It could otherwise seem that we are further abusing people with learning disabilities with intrusive procedures, rather than stopping the perpetrators of this problem.

It is important that the risk of pregnancy is assessed, before the decision to sterilise somebody with a learning disability is reached. If it has been established that there is a likelihood of pregnancy then there may be a number of points to consider.

Contraception

Using sterilisation as a permanent form of contraception may be inappropriate. There are a number of other forms of contraception, which are extremely effective. In some cases it was argued that there are risks involved with these types of contraception, e.g. the combined pill has associated risks of deep vein thrombosis. Furthermore, the reliability of these forms of contraception is not as high as sterilisation. These risks need to be offset against the risks of sterilisation, which involves a general anaesthetic and future psychological risks in terms of this operation being irreversible. In some cases, sterilisation may also worsen menstrual cramps. A further point to consider is that new technology may be available in the future which may offer reversible forms of contraception, which are as effective as sterilisation (Belfield, 1999).

Trauma

In some court cases it was cited that people with a learning disability would find childbirth too traumatic and therefore sterilisation was necessary. It has been found that a number of women experience trauma following childbirth. Estimates by Czarnocka and Salde (2000) suggest that between 3 and 6% of women will display symptoms of post-traumatic stress disorder following a birth. A further percentage will display some symptoms of distress.

Post-traumatic stress disorder refers to a cluster of symptoms, which occur in response to a traumatic event. This event should be something “that would evoke symptoms of distress in most people and is outside the normal range of usual experience” as cited in the Diagnostic and Statistical Manual of Mental Disorders.
(DSM-III-R, 1987). Symptoms include: persistent re-experiencing of the event; avoidance of stimuli associated with the event; increased physiological arousal, with symptoms lasting for more than a month (Creedy et al., 2000).

Can the court then justify sterilisation of somebody with a learning disability on the grounds of pregnancy being too traumatic? Firstly, if there is already a significant proportion of the population experiencing symptoms of post-traumatic stress, should they also be considered for sterilisation? It seems unlikely that traumatic stress would be cited as reasons for sterilisation unless someone had a learning disability. A key issue is whether having a learning disability makes it more likely that trauma will be experienced during birth. The research suggests not. Factors that were identified as precipitating post-traumatic stress disorder following childbirth were: extreme physical trauma or pain (Ballard et al., 1995); no presence of a supportive birthing partner (Klaus et al., 1986); fear for the child’s life (Creedy et al., 2000); prolonged and difficult labour (Ballard et al., 1995); feelings of being less able to cope (Czarnocka and Slade, 2000); feelings of powerlessness during the procedure (Ballard et al., 1995); prior mental health problem (Czarnocka and Slade, 2000); discontentment with the level of care given in hospital (Creedy et al., 2000); the pregnancy being unplanned (Czarnocka and Slade, 2000); a history of infertility/difficult births (Moleman et al., 1992); and the mother experiencing abuse prior to pregnancy (Records and Rice, 2002). Whilst some of these factors may be slightly over-represented in the learning disabilities population, e.g. prior mental health problem (Hassiotis et al., 2000), some factors may also be protective, for instance, having a learning disability might make someone less aware of damage that the child may sustain during childbirth. Allowing sterilisation on the grounds of a birth being traumatic then needs to be evaluated on a case by case basis. This point is highlighted in the article by Baum (2000) who described how a female with learning disabilities and a low level of cognitive functioning coped extremely well with childbirth, despite low expectations from professionals.

Ability to Parent

A number of authors have questioned whether someone that is unable to parent a child should give birth to a child (Gillon, 1987). Again, the point is raised that if someone does not have a learning disability, a decision to sterilise would not be made based on parenting abilities. According to the Department of Health figures (Children Looked After by Local Authorities, Year Ending 31st March 2001), approximately 52 children per 10,000 of the population were under some form of care order (adoption, fostering, children’s homes etc.). It seems unlikely that their parents were considered for sterilisation. The Human Rights Act (1998) states that all people have a right to have a family. This being the case, difficulties in parenting abilities is something that social services should be supporting, in the same way that they might support parents who have physical disabilities with parenting.

One consideration may be the impact of giving a child up for adoption, or fostering on the parent with learning disabilities, if this is a for-gone conclusion. The research into the effects of giving up children for adoption is quite limited. However, the suggestion is that birth parents who have been subject to both voluntary and involuntary termination of their parenting rights were likely to suffer long-term adverse psychological consequences, such as feelings of isolation and emptiness (Mason and Selman, 1997, as cited by Freundlich, 2002). Having said this, if somebody does become pregnant, they may opt for termination rather than adoption, in which case ability to parent is irrelevant. Again though, this procedure carries
its own risks of trauma and physical health risks (Bernard, 1990).

Assessing the client’s understanding of Pregnancy Issues

The client’s understanding needs to be assessed, in looking at the following areas:
1. Does the client understand how people get pregnant?
2. Has the client previously been pregnant. If so what is her understanding and experience of this?
3. If the client does not understand pregnancy, could she be supported to do so. In order to establish this, an assessment of her previous learning, her willingness to learn, and her retention of knowledge must take place.
4. Does the client understand that pregnancy can be prevented?

The following also need to be assessed: the possibility of trauma if the client gives birth; the risk to the mother’s physical health arising from pregnancy; the ability to parent and the impact of giving up a child for adoption; and the possibility of other forms of contraception.

Conclusion

This article has not looked at the issue of the rights of the unborn child. However, case law does not examine the rights of third parties in issues of consent and this article aims to look at legal concerns of the decision to sterilise rather than moral or ethical issues. Further exploration of the ethical and moral elements of this area would be useful.

Once all the key areas in determining whether sterilisation should take place have been carefully considered and weighed up, the key question must then be, is this operation still in the best interests of this client? In this way, we move away from the unethical sterilisation procedures that were almost routinely imposed upon people with learning disabilities by others, to an individualised process which it is hoped will be the right life decision for an individual. Brady and Grover (1997) argue that it is simply “good faith and ordinary prudence” that informs us whether sterilisation could be described as therapeutic and in a woman’s best interest. They propose one simple question: “would sterilisation be recommended but for the girls’ intellectual disability?”

Summary

This article has attempted to demonstrate the complex nature of understanding and subsequently assessing an individual’s capacity to consent to sterilisation. Also, if it is deemed that an individual is without this capacity, we have attempted to review key areas of consideration in determining whether this procedure would be in the person’s best interests.

The two key areas when assessing consent to sterilisation procedures of somebody with a learning disability appear to be capacity and “best interests”.

Capacity

This area includes the ability of the client with a learning disability to consent to sterilisation procedures, understanding of sterilisation, understanding of pregnancy, influence of others etc. Outlined in this article are the most significant areas of consideration when hoping to achieve a thorough assessment of capacity.

‘Best Interests’

Determining best interest involves weighing up the risks and benefits of having and not
having the procedure. These risk-benefit issues include:

• the likelihood of the client becoming pregnant alongside the use of the least invasive procedure to manage contraception
• the risk of trauma arising from pregnancy and the subsequent birth of the child
• the trauma of being sterilised and the subsequent loss of the right to have a child and family in the future
• the degree to which the person would have the capacity to parent a child and what if any support they would need to achieve this
• the mental well being of the client resulting from the points above.

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