# CLINICAL CONUNDRUM: WHAT WOULD YOU DO?

## Reproductive issues and learning disability: different perspectives of professionals and parents

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### Introduction

The reproductive rights of adults with learning disabilities raise complex social, ethical, moral and legal issues. In this article various professionals and two parents express their views on a real-life ethical dilemma. (NB. Names have been changed to preserve anonymity.)

### Clinical scenario

Melanie is a 25-year-old woman with Down syndrome. She requires help with the normal activities of daily living and lives with her parents, who receive the highest level of attendance allowance. Her boyfriend, Tom, also has learning difficulties. They have been in a relationship for 3 years and Melanie has had an intrauterine device (IUD) inserted for contraception. Melanie comes to see you on her own to ask you to remove her IUD: she and Tom have decided that they want to have a baby. From the conversation you get the impression that perhaps Tom wants the baby more than she does, but she does not confirm this. What would you do in this situation?

### The panel

The five discussants listed in Box 1 were asked how they felt this situation should be managed.

**Box 1: Invited discussants for the clinical scenario**

- Consultant in family planning
- Training manager for a national sexual health charity
- Ethicist
- Mother of learning-disabled woman
- Mother of learning-disabled man

*Consultant in family planning*

My first thought about this case is to assess Melanie's competence to consent to procedures. Although we are told that she requires help with everyday living, she has in fact come to the clinic alone. In order to plan a journey to a clinic with a specific task in mind, Melanie has already displayed a good degree of competency.

It would be interesting to know if she consented to the IUD insertion, and if she did she must have been assessed competent to consent at that visit.

I am concerned that the reason for IUD removal is coming from Tom rather than Melanie, so I would not remove the IUD at this initial visit, but arrange to see them together and of course separately at the next available opportunity, in order to find out the reasons behind this request. I would explain my reason for this second visit to Melanie, emphasising that I am not rejecting her request, but making sure that it is really what she wants to do.

I think that whether or not Melanie attends again will show her determination or not to have the IUD removed.

*Training manager for a national sexual health charity*

First of all, it's great that Melanie has a boyfriend and a sex life. This valuable aspect of normal adult life is so often difficult for disabled people who live with their parents.

It is hoped that she and Tom would have previously received sex and relationships education (SRE) to ensure that they can make fully informed choices about sex and sexual health, and that elements of this may be ongoing as developmental needs change. Ideally, SRE would thoroughly address parenthood, all its responsibilities and how contraception decisions are shared between partners.

However, it is more than possible that Melanie has not received such thorough education, and is inadequately prepared for this important decision. Even if her choice is uninformed she has the same right as any other patient to make plans that alarm her doctor.

Asking for an IUD to be removed seems to me as a layperson to be ethically different from, for example, refusing the next routine injection of Depo-Provera®, where to proceed would of course be an assault. Before removing an IUD the doctor needs to be ready, and being ready can include being sure that removal will not harm the patient.

So Melanie should be told that everyone planning a pregnancy should ideally get ready first, and be sure that it is the right decision and the right time to go ahead, and that everything practical is in place for looking after a child. Melanie's consent should be sought to contact her key worker or support staff about setting up some intensive education and reviewing the support needs potentially required at home. It is always possible that Melanie's parents know about and approve this decision, and the family want to help her look after the baby.

Another possible scenario is that a baby is seen by Melanie and/or Tom as representing normal family life, and would lead to them living as a couple free from family or professional interference. It could be that helping them to find a way of living together as a couple with appropriate support would meet this need, and the responsibility of child care is not really what they want.

Offering education, support and a review of the couple's living circumstances as a preliminary to removing her IUD is not discriminating against Melanie: it is seeking to meet her additional needs. If she refuses this help, or accepts it and still decides she wants to proceed with a pregnancy, then she has the right to have the IUD removed as soon as can reasonably be arranged. Services will then have to work with Melanie and Tom to prepare for the future.

*Ethicist*

Key to your decision on how to act is your judgment as to whether Melanie is competent to give consent for removal of her IUD. One would need many more facts before reaching such a judgment, for example:

- The level of Melanie's disability and potential parenting skills.
- The quality of support from her family.
- The kind of learning difficulties Tom has (many learning difficulties are compatible with being a good parent).

- The likelihood of a potential child being removed from Melanie's immediate family and the effect this would have on her.
- The degree of strain that being allowed to keep the child would put on familial relationships and how Melanie would cope with this.

It would be interesting to know whether Melanie was deemed competent to provide consent when the IUD was inserted. Although, even if she had been, this doesn't necessarily mean she is competent to have it removed, as competence is not an 'all or nothing' matter. You can be competent for some decisions but not for other more complex ones, and the decision to have an IUD removed in order to have a child appears more complex than the insertion of a device for contraceptive purposes.

Making a decision on competence can be notoriously difficult, and a pitfall doctors can fall into is pronouncing patients who are out of line with their own values non-competent. One might feel quite strongly that Melanie should not have her IUD removed but if she is able to understand and retain information relevant to her circumstances and has the ability to weigh it up and reach a conclusion, then she is competent for this particular decision.

For valid consent one not only has to be competent and fully informed but also non-coerced, so the impression that Tom wants the baby more than Melanie demands attention. If the doctor was still concerned after seeing Melanie alone then perhaps Melanie would consent to her parents being consulted. Strictly speaking, if Melanie was deemed competent then she should be allowed to refuse the involvement of her parents, but if one was seriously concerned about coercion, the doctor would be able to justify a breach of confidentiality by claiming he or she was acting in Melanie's best interests.

If Melanie was judged to be non-competent then the doctor is required to act in her best interests as no one else can give consent for an adult. One could, therefore, decide not to remove the IUD if it would, all things considered, not be in Melanie's best interests to become pregnant and have a child.

There are some ethicists who would argue that even if Melanie does understand what having a baby involves, and it is judged that she can make a decision about having her IUD removed, then the doctor still has a right to refuse (just as a doctor has a right to refuse to perform an abortion) on the grounds that they do not want to cause serious harm to another potential person.

*Mother of learning-disabled woman*

I would worry about both Melanie and Tom. If Melanie is not able to look after herself and Tom also has learning disabilities, I would worry that they did not understand the full implications of what they wanted. I would try to have some time out with Melanie, mother to daughter, to see just how much she understood. We would need to talk frankly. My overriding concerns would be for Melanie's physical health but also her emotional health. There may be implications for the wider family, myself and maybe for Melanie's brothers and sisters. They may find in a few years' time that they had another child or teenager to consider in the family, especially if Melanie became ill, could not cope or indeed if she should die in her 30s or 40s. I really would not want my daughter to be in that situation and I would try to discourage it at all costs, and try to enlist the support of the general practitioner (GP). Of course, if it ever should happen then I would be a proud grandparent and give all my support where I could.

*Mother of learning-disabled man*

How able is Melanie to cope with the demands of a baby, even a 'normal' baby? How badly affected is Tom? 'Learning difficulties' is a very wide definition. How willing are the prospective grandparents to undertake the responsibility of sharing in the care and upbringing of a baby? Genetic assessment must be sought before any definite decision can carry moral weight. It might be that even the chances of conception are small. Both she and Tom must be consulted, not just Melanie.

From the point of view of a parent who has been faced with similar circumstances, I was adamantly against the possibility of offspring. My influence was strong enough to sway my son and his girlfriend's mother to agree with my point of view and to persuade the acceptance of contraception, strongly advocated by our GP.

Finally, may I say that, in such a conundrum, the parents' point of view and decision are always emotionally charged, and a physician's advice/decision must take account of this fact.

**Discussion**

The members of the panel all stress the need to assess Melanie's competence to consent, the extent to which she is being coerced, and the ability of both Melanie and Tom to care for a child. This may take some time and should ideally involve discussion with the couple, their families, GPs and other carers. It is clear from the parents' comments how difficult and emotive such situations can be.

**What was the outcome in this real-life scenario?**

The doctor removed the IUD but the patient re-attended a few weeks later asking for it to be replaced.

What would you have done faced with this situation? We welcome your comments.

**Useful resources**

Materials to support education for people with learning disability are available from fpa. These include books for parents and staff, covering topics such as puberty, sex education, sexuality and relationships. fpa also runs courses for staff who work with learning-disabled people (see http://www.fpa.org.uk for details).

**Acknowledgement**

The author would like to thank the panel for their input. A listing of all the individual panel members who have contributed to the Clinical Conundrum section of the Journal appears below.

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**CLINICAL CONUNDRUM PANEL MEMBERS**

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