To Whom it May Concern,

Let me start by apologising. I am going to try to write this letter without being too emotional, but this is a very emotional subject and I am sure that I will be. I personally don't believe this topic has a right or wrong opinion. Every person will have a different life experience, a different level of interaction with this topic, a different experience of dealing an intellectually disabled adult, a different professional view. And that's ok. It is what makes us human and it is what makes us care. But please, remember that we are all different when you make your recommendations.

Let me give you some background on my family. My older brother has an incredibly rare genetic mutation. He has 48 chromosomes. It turns out that 46 really is quite a specific number and more is not better in this case. He presents somewhat like he has autism, which is often what we call it in order to help explain his behaviour to people who don't know him. But it's not autism and he does not have all those traits. He has been tested recently and definitely falls into the moderately intellectually disabled category. My sister is the oldest in my family, followed by my brother, and I am the youngest. There is a significant age gap between the other two and me. Please remember that all my life I have only known life with a disabled brother. For better or worse this has helped to shape my opinion on this topic.

I realise you are talking about sterilization for girls, but if I could pay for my brother to have a vasectomy I would do it in a heartbeat. Gladly. My brother discovered the world of dating and girls only recently. This is because despite the fact that he is a 40 year old, he has the emotional and intellectual reasoning of roughly a 16 year old. Feel free to think back to your attitudes towards sex at that age.

My family and I fully support him having girlfriends (although only one at a time. We also talk about appropriate ways to treat women). We help him to buy Christmas and birthday presents for them, have his girlfriend over to dinner, discuss appropriate ways to end the relationship when he wants to and talk through possible pros and cons of living with his girlfriend if he wants to. We celebrate that he has reached this social milestones and has a social life. We encourage him to get out and about and meet people. He does this by going to disabled sport leagues and through support groups.

We are also open and encouraging of his sexuality. Although it is quite awkward to have to talk to your older brother about safe sex and sexually transmitted infections, I have done it. Openly, frankly and answering any questions. My sister and brother-in-law have also done it. Again, in more detail than you ever want to talk to your brother about such things, but he is who he is and he needs that information.

However, with the right to have sex and explore your sexuality also comes the responsibility to either do it safely, or deal with the consequences. That consequence could be an infection or a baby. My brother is like most teenage boys (remember, mentally that is what he is) and doesn't like using condoms. In fact, let's be perfectly honest, there are many men out there who are not going to be the ones that initiate the use of a condom if they don't think they have to. My brother is the same. His girlfriends have a similar level of cognitive reasoning. They aren't going to insist on it. They don't insist on it.

I am not sure whose fault this is. Is it ours for not being open enough in the safe sex talk? Is it theirs for not thinking about the consequences? Is it no one's fault because we are not there and they don't have the ability to reason it through? Regardless, the end result is the same. Most of the time I am pretty sure my brother is not having safe sex.

So let's discuss the consequences. If he has an infection he does not have the skills to easily make a doctor's appointment. This means he has to talk to my mother about it. To be fair, that's a pretty horrible discussion for anyone. It's not likely to happen which means the infection will go undiagnosed and untreated. This means it has a higher chance of being passed on to the next girlfriend. I know sterilization will not solve this problem and I will continue to have safe sex discussions with my brother on a regular basis. I will also contact his doctor to ensure he asks those questions whenever my brother goes to see him about anything.

The other consequence is having a baby. This is what many families of intellectually disabled people are most concerned about. That baby has rights too. My brother is not capable of caring for a baby. I say this in full honesty, knowing that others in the community will judge me and say that I am not supportive of my brother. I am. I also know he forgets to feed the cats regularly, needs reminders to clean his teeth and thinks that baked beans and coco pops make a nutritional diet. He gets exceptionally agitated if he can't have significant periods of time on his own as he finds social situations tiring. He tends to spend about two hours with his girlfriend before he needs time out. My brother does not have full time employment and his contract work as a labourer is tenuous and poorly paid. He has incredibly poor literacy and numeracy and below average reasoning skills. All of these traits indicate he will struggle with the needs of a child.

My brother can't have a "normal" child. His DNA is affected and he will pass on faulty DNA. In my experience special needs children have different care requirements that can be more taxing on the parents. My brother struggled to cope with my perfectly healthy niece for more than twenty minutes when she was a baby, the chances of him coping with full time fatherhood are slim to be polite.

Let me ask you; if my brother has a child, who will raise it? My mother – who is in her seventies? My sister – whose own child is now near the end of high school and is looking forward to the next phase in her life? Myself – who doesn't want children? The state – where most people agree that family is best and the chances of a disabled child being adopted are slim? My brother – remembering that he will need overwhelming amounts of support and assistance which quite frankly the state doesn't have the money for? His girlfriend's family – who face all the same objections that we do?

If it came down to it, we would care for that child and they would be loved. What we would like though, is for the issue to never come up. That hypothetical child has rights that we can protect for it. As a family we also have the right to own lives and choices. Again, I am sure there are members of the community that will judge me for saying that. But do you live with your brother and look after him? Will you do that until he dies because there are not enough assisted living spaces provided by the government? Are you happy for your life to be influenced by choices made by your brother? We are and we do it. What we would like however is to limit the impact that his choices can have on our lives and the lives of his hypothetical children.

I understand that the medical profession has abused the right to sterilise females in the past. It is abhorrent and I condemn it. I also think the medical profession has changed enormously in recent years and there are not many surgeons who would abuse the system any more. I also think the majority of families that would like their disabled members sterilized are in the same boat as my family. We love them, we support them and we would like them to be able to exercise their right to explore their sexuality in a safe way.

Realistically other contraceptive methods have some problems. It can be tough to remember to take a pill every day; it is the parent who will remember about an injection every 12 weeks which is fine while they are alive but fraught with danger once they are not; the implant is quite painful to both insert and remove (from experience) and can lead to other side effects. For some women, and men, sterilization is a good choice. For many reasons.

Please, when you make your recommendation, remember each person and each case is different. There can be no firm rule to govern this. I believe each case should be assessed by a panel of doctors to ensure the right choice is being made. That panel may, and should, include a social worker or an advocate who works solely for the patient to protect their rights. If we accept that intellectually disabled people have lower cognitive abilities then surely it follows they will also have more difficulty giving a fully informed consent to the procedure. This is why I would suggest that a patient advocate be appointed to them. If the panel says no to the operation then so be it, but there must be the option for women and men in this situation. Each situation also needs to be thoroughly investigated in its own right. There is no else quite like my brother and his case is unique.

If the panel does not agree to the operation I would also ask that they recommend alternatives and support to the family. Most families will only pursue this option as a last resort and will need help and advice as to other options available. This should include both medical procedures and counselling by professionals that are trained to work with both families and disabled people. In our experience it has been overwhelming difficult to provide counselling for my brother by a trained professional who is able to work with a disabled man. As a family that has tried to give this support it is both frustrating and heartbreaking that it is not readily available to the average person.

I fully understand how serious sterilization is and at no stage should that be underestimated. I do not think the procedure should be entered into lightly or without serious professional consultation, but I would expect that for any man or women considering the procedure. Please do not associate my support of this procedure as belittling the abilities and rights of disabled people. I also do not also think this is about mitigating the effects of sexual abuse; that should always be punished to the full extent of the law. I support this because as the sister of an intellectually disabled man with a genetic mutation, I do not believe he can adequately care for a child. The level of support he would need is extraordinary and is not available through the government leaving it in the hands of the family. In that case, surely the family has some right to request that he is able to enjoy his sexuality with a level of responsibility?

I also realise that many in the community will decry the carers who ask to have their rights in this considered. The large majority of carers do an incredible job. They are paid next to nothing if they qualify for assistance, they do this job 24 hours a day and they do it for years, if not a lifetime. Before you call them shallow and selfish for not wanting to take on another baby, please consider your everyday life. You may well be a carer, and in that case I take my hat off to you for the

commitment you have made. If not then imagine doing your everyday life while looking after someone, to some extent, all day. And now put a baby in there as well. Most carers of disabled people are parents, like my mother. She is a grandparent, she is tired and is not up to fighting for the rights of another disabled child, which all parents of disabled children end up doing. It is not fair as a society to ask her to take on another baby, and it is not fair to the baby to place them in state care. So what is the answer if there is a baby?

Society will talk about the rights of the patient, but with every right comes a responsibility. We would like our family members to have the right to sex and give them a way to do it responsibly.

Thank you for your time. I do not envy you being on this committee. I think it is an overwhelming task you have in a very sensitive area. Please understand that I have chosen to remain anonymous not because I am ashamed of my viewpoint, but because my brother doesn't need to be identified. His life is tough enough as it is. Good luck with your recommendation. You have the power to influence the lives of so many people both directly and indirectly and I hope you consider carefully.