
Choice and Consent in Prenatal Testing in Australia

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Abstract

In many liberal democracies, the moral principle of reproductive liberty or choice has an unprecedented ascendancy in the management of reproduction, especially in regards to prenatal testing and decisions about selective termination. Drawing on qualitative data on ultrasound screening in Australia, I show that notions of choice are deployed in various ways, and in the process, do various things. In particular, the “apparatus of choice” positions women as the principal moral agents in prenatal testing regimes, and the fetus as a kind of moral boundary object, while deflecting moral responsibility from clinical practitioners. Further, I consider whether a consistent and explicit consent procedure for (non-invasive) prenatal testing is required in Australia, given the current lack of consistency in procedures for ultrasound screening and cell-free fetal DNA (NIPT) testing.



1. Introduction

I'm going to talk primarily about a project that I have been doing the last couple of years funded by The Australian Research Council, which is the main government funding source in Australia. It is a project that I've been running with a colleague of mine, Dr. Stephenson who works in Public Health at University of New South Wales in Sydney.

It is partly an empirical project on obstetric ultrasounds and we interviewed a number of women and clinicians involved in the practice of obstetric ultrasound. I'll talk a little bit more about that in a moment. But more generally, I'm interested in developing an approach bioethics that draws on the tradition of continental philosophy. My work is particularly influenced by Michel Foucault, the French philosopher. So in some of my other work I use the concept of biopolitics. I'm not sure how popular that concept is in Japan, but it's become quite popular in Australia and other places. And I have been using that concept to think through some of the issues around prenatal testing technologies.

Now I will talk a little bit about what that concept means in a moment. But basically, what I think is that prenatal testing is actually inseparable from what I call biopolitical decisions about who comes into the world. So we make decisions, prenatal testing allows us to make decisions about what we're going to do about a pregnancy. It varies on context, of course, but it seems to me that there's a very strong link between prenatal testing and termination of pregnancy for fetal abnormalities. Because, one of the key reasons for prenatal testing is to diagnose fetal anomalies or abnormalities. In different contexts, this allows us to do various things. But whatever that context allows us to do, the decisions that we make are decisions about who comes into the world.



Now in bioethics, these decisions about pregnancies and termination are often seen as been based on questions of individual freedom and right, where freedom is understood in terms of individual or parental choice. So there is a very strong emphasis in bioethics on individual choice and we'll also talk a bit more about how that comes out in a clinical context in Australia in just a moment. Now the framework of individual choice that we're talking about in bioethics is primarily one where individual choice is understood as negative freedom, that is freedom from interference. So the main imperative then is to make sure that no one else is impeding the free choices of individual.

I'm very interested in this this emphasis on individual choice in prenatal testing decisions. But I'm not going to approach the question of individual choice in a standard way. I'll take the standard way to be concerned with whether the choices are really genuine choices, or with whether they are really free choices or so on. I want to take a slightly different approach which is to say, what effects does the emphasis on individual choice actually have? So what are the social and subjective effects of that emphasis on individual choice? So I'm going to draw on work of Michel Foucault, the French philosopher, to draw out the notion of an 'apparatus of choice'.

So I'm going to argue that at least in the Australian context, in relation to prenatal testing there is something that we can identify as the Apparatus of Choice. There's a very strong emphasis on choice and this comes out in various kind of discursive and material ways. And this apparatus operates in particular ways to do particular things. So we're interested in the effects that an apparatus of choice has.

And I going suggest that the first thing that we see

when we look at or approach this question of what an Apparatus of Choice actually means, is that it reveals a very complex, kind of interaction of affect, ethics and normalization. In prenatal we get the three different aspects of moral or ethical principles, individual desires and emotions and the normalizing aspect of prenatal testing operating together. As well as this, though, I argue that the apparatus of choice also works to reinforce existing ways and patterns of discrimination.

The most obvious one is the pattern of discrimination on the basis of disability, but there are also more subtle ones based on socioeconomic status and cultural capital. So that comes out in different ways as well.

The thing that I am particularly interested in, in terms of thinking about the effects of the Apparatus of Choice, is mostly the effects for pregnant women. Now I'm going to suggest that what it primarily does for pregnant women is make them the main or sometimes even the sole moral agent for decisions about prenatal test. So it deflects moral responsibility from clinicians and places the moral burden of prenatal decision making on pregnant women. Now on the one hand that's a good thing, because we want women to be free and have the prerogative to make those decisions for themselves. On the other hand, it means that the responsibility of anyone else involved in that apparatus is not recognized.

So let me just say a little bit about the context of prenatal testing in Australia to begin with. The most widely used prenatal test in Australia is obstetric ultrasound, which is performed in almost in every pregnancy at the 12-week mark and the 18 to 20 week mark of gestation. Australia has – you may know this already - but Australia has both a public healthcare system and a private healthcare system.



When it comes to ultrasound provision, mostly that is done through private clinics, but at the same time some of it is done in public hospitals, for poorer women in particular. But private clinics primarily provide ultrasound scanning in pregnancy. Those are still subsidized by the public healthcare system, by Medicare. So even when the scan is done in the private clinic, it's subsidized by Medicare.

At the same time, if women go through the public system to have their child, which a lot of people do, you will still go to a private clinic to have an obstetric ultrasound, for the most part. Some women go through the private system for their maternity care, in which case they have their own obstetrician, and the obstetrician might perform a lot more ultrasounds during the course of their pregnancy but these won't necessarily tell you much about the fetus apart from the fact that is alive.

In pretty much every pregnancy in Australia, there is at least one ultrasound scan at the 20-week mark. This has become a routine scan, which means it is very well subsidized by Medicare. It costs very little. For a lot of women, it's actually free. The first trimester scan is not technically routine but almost every woman has it. That's done in conjunction with a maternal blood test to detect the levels of hormones and so on in the blood. Some women decide not to have this because they don't want to know about Down syndrome, but most women will have it.

So ultrasound is the most common prenatal screening test. But in addition to this we have the kind of standard invasive tests like chorionic villus sampling and amniocentesis. Most recently in Australia, we've also seen the introduction of NIPT, or what's called NIPT, cell-free fetal DNA test. The introduction of this in Australia was very different from in Japan in that there's been almost no public discussion on it. It's just become available in some

private clinics but not in others – no government decision about the introduction of NIPT, there's no national statement from the obstetricians and not much discussion about how it should be introduced. There's lots of discussion amongst the obstetricians about how it should be introduced into the current regime of prenatal test, but there's no public discussion about it – almost no public discussion.

So as I said there's a very well established regime of ultrasound screening at 12 and 18 weeks available in both public hospitals and in private ultrasound or radiography clinics. And those ultrasound tests are subsidized by the public healthcare system. There's no subsidy for other screening tests like NIPT. So the cost of those is covered by the people who decide to have those tests.

Now there are national guidelines for ultrasound testing provided by the Australian Society of Ultrasound Medicine and the Royal College of Obstetricians and Gynaecologists. But these are only guidelines. And most obstetricians will say that they are kind of baseline guidelines. They're just minimal standards of care. They don't actually determine what kinds of things are tested for in an ultrasound. So they don't actually – they don't necessarily outline what a clinic – any particular clinical test – will actually look for. For instance, in recent years a number of clinics have been – when they are testing for Down syndrome level also mention the nasal bone, which is being determined to be a soft marker for Down syndrome. So as well as the nuchal fold at the back of the neck they will mention the nasal bone. But not every clinic does that. It's not required in the guidelines and not every clinic would do it. Really, there's a number of private clinics that lead the way – they will look for different markers in their scans and that will probably eventually flow down to broader practice. At the same time, though, there is an ongoing accreditation process – anyone providing

obstetric ultrasound has to have ongoing accreditation in order to be able provide a service of appropriate diagnostic standard. And that accreditation is provided through the Royal College of Obstetricians and Gynaecologists.

Another main question that is emerging at the moment or that's part of the conversation of obstetricians in particular is just how the introduction of cell-free DNA testing should be aligned with the ultrasound testing. It's very unclear exactly how that test fits with current practice, or what the added value of that test actually is – what new information it provides apart from those tests, who should be recommended to have that test. Cell-free DNA testing, who will want to have that test and so on those things are a large conversation for obstetricians. But there's really not very much public discussion about it. But I want to mention that when I talked with obstetricians about it, one of the things or one of the effects of that testing, of NIPT testing, is that its changing the rationale for first trimester screening itself. That has been understood primarily as a test for Down syndrome. That's changing with NIPT because that's what NIPT can do with significantly higher rates of accuracy. So what's happening is that the first trimester scan is expanding to cover a range of morphological characteristics or fetal structural characteristics and at the same time also becoming a test for conditions that might emerge in a pregnancy. So it's becoming a predictive test for preeclampsia. So it's starting to be used to look in advance for ___ pregnancy complications, things not necessarily related to the fetus – the placenta for instance. So it's changing

Now one of the things that I find very interesting about the introduction of NIPT is that to have an NIPT test, you need to sign a consent form. You need to be provided with information about the test, you need to at least have some understanding or say that you



have some understanding about what that information is, and so on for informed consent. But the interesting thing is that you do not have to sign a consent form for ultrasound.

NIPT tells you essentially the same information as the first-trimester scan - but you don't need to sign a consent form for one of those tests and you do for the other. So it seems to me that there's an interesting question here about what the actual principled difference is between these two approaches to non-invasive testing. And if there isn't any principled difference, what should Australia actually do - would it be better to have a coherent system and if so, of what kind? We need to decide whether that should mean to introduce consent forms for ultrasound testing or get rid of them with the NIPT. Or perhaps we should just kind of go with what's there ...

To bring this back to what I call to the apparatus of choice, I want ask whether having an explicit informed consent process for ultrasound would actually diminish some of the more negative effects of the apparatus. So that's the question we'll get to – that's bringing those two questions of choice and consent together.

2. Biopolitics

The first thing I want to do then, given my background in Continental Philosophy and Bioethics, is actually establish the bio-political nature of prenatal testing, so I'm going to talk a bit about the concept of bio-politics. As some of you probably know the idea of biopower derives from the work of Michel Foucault, in particular, his book *The History of Sexuality*, in the first volume. There's a very short section at the end of that book where he talks about that concept. And he argues at the end of that book, that during the 18th century there was a change in the way in which power operated. But he argues that



there became much less emphasis on sovereignty and the power of the sovereign to make decision about ending life basically. And he argues instead that the way in which power operated actually changed to a power that was focused much more on fostering life, on making – or improving the health of population – improving health and well-being, rather than simply deciding on whether to kill. So he argues that the ancient rite to take life or let live was replaced by a power that focused on whether to foster life or disallow it to the point of death. So the basic idea of biopower is that it's a productive power, that actually is interested in maintaining and promoting both individual and population health and well being. And he argues that there are two kinds of – two elements to biopower. Am I just telling you stuff you already know? Is everyone familiar with bio – no, it's okay?

So he argues in this book that there are two aspects to biopower, one of which he calls disciplinary power. So this is related to Foucault's work on the prison system. And that of focuses on individual bodies. It's focused on making individual bodies act in certain ways. The other kind of power that he talks about though is what he calls biopolitics and biopolitics not interested in individual bodies per se, but interested in population well-being, population health. One of the crucial things that happens in Foucault's story is that statistics emerged as a discipline. Once you have statistics you can actually know things about large groups that you would not otherwise have known, because of the capacity to make predictions on the basis of numbers basically.

So that's part of the story that Foucault tells here about the rise bio-politics. But he also argues throughout the first volume of *History of Sexuality* that biopower, which means both discipline and biopolitics, is tied to what he calls the deployment of sexuality. Sexuality becomes really crucial to

biopower; he argues that sex was a means of access both to the life of the body and the life of the species, so he suggested that biopower is interested in individual conduct in relation to sex, but also that it's important for population health because of its population outcomes. So sex in Foucault's picture is very, very important in terms of tying together discipline and biopolitics. He argues that sex is actually one of the four main axes of biopower – or what he calls the “socialization of procreative behavior” is one of the four great strategic unities that form the mechanisms of health focused on sex. So he gives us a picture of various kind of aspects of the deployment of sexuality, and this socialization of procreative behavior is one of them.

And he argues that this kind of socialization has two aspects: A political socialization through what he calls the responsabilization of the procreative couple – making them responsible for population well being. And secondly, a medical socialization through pathologization. So the pathologization of certain conditions, certain modes of conduct, making them abnormal essentially. So we have the emergence of these concepts of the normal and the pathological. So some of you might be familiar with the work of the French historian of medicine Georges Canguilhem, who has a very interesting book called *The Normal and the Pathological*, which gives you really interesting history of the emergence of those concepts and that history is important for Foucault's account of biopower, it seems to me, and particularly this idea of pathologization.

Now obviously, the kind of things that we're talking about when we talk about reproduction today a vastly different from the picture of reproduction that Foucault was working with. Foucault was primarily focused on the 19th century and reproductive practices have changed a lot since then. And while I can't give a complete picture of how

those have changed, partly because it would take a very long time, partly because it would be impossible anyway, I think there are a number of things that are worth pointing out. The first one of these is what I'm calling the technologization of reproduction. So obviously depending on your concept of technology this could be as broad or as narrow as you like, but technologization is something that's been happening in reproduction for either a very long time depending on how you understand technology or a shorter time.

But either way one of the crucial turning points I think in this technologization is the development of IVF. IVF allows us to precipitate fertilization outside the maternal body and this has enormous consequences. It then leads into the second great change, which is that of commercialization. So, commercialization - which refers to the development of oocyte markets, the development of the sale of reproductive tissue of various kinds and ultimately, the development of the commercialization of the products of reproduction in surrogacy - all of these practices are in some ways linked back to IVF.

So I think IVF is a really crucial turning point in the technologization of reproduction. The third thing that I think has changed is this – in reproductive practices there is a very heavy drive toward normalization and I think prenatal testing actually plays a really crucial role here and in particular obstetric ultrasound, just because it's one of the oldest ways of testing the fetus available. And by normalization I'm drawing on – again I'm drawing on Foucault's work. So Foucault talked a lot of normalization both in his book, *Discipline and Punish*, and in his work on biopower. One of the central characteristics of biopower is that it is a normalizing power, it works through norms rather than primarily through the law and legal institutions. So in Foucault's picture of biopower, sovereign power worked through law, while biopower worked through norms and biopower is ultimately



intrinsically normalizing, which is to say that it tries to make things normal. That's the simplest articulation of that. It's interested in the constitution of a normal in various ways, identifying the normal and the abnormal, and potentially eliminating the abnormal.

And I think in terms of prenatal testing, ultrasound is really a preeminent normalizing technology, that's what it does. It works in two different ways to normalize fetuses – firstly, it works to generate, it helps to formulate knowledge of what is normal– ultrasound is crucial to the generation of normal range parameters. You couldn't understand normal fetal development without ultrasound. That was a really groundbreaking moment in terms of understanding fetal development, just being able to see the fetus, because otherwise that kind of knowledge just wasn't available. So in a way ultrasound is normalizing just because it allows us to understand the norms of fetal development, the kind of patterns of normal development versus pathological or abnormal development.

But it's also normalizing in a negative way when prenatal testing or ultrasound in particular has become tied to termination of pregnancy. This is a kind of negative normalization, if you like, whereby the production of normal range measurements has then been mobilized in particular ways or embedded in a social context and a legal context, whereby the abnormal has been eliminated through termination of pregnancy. So this control of the abnormal is a kind of negative aspect of normalization or a negative side to normalization I think. so that's the kind of double aspect to the way in which ultrasound is a preeminent normalizing technology.

Now the way in which ultrasound actually works today is that it also necessarily operates within a context of the medical management of risk and uncertainty, so there's questions about risk in

relation to Down syndrome, there's questions of uncertainty because ultrasound is not actually a diagnostic technology, its primarily geared toward identifying soft markers for various conditions which then can be diagnosed using other technologies.

But there's also other aspects to uncertainty where, when we talk to a lot of the obstetricians and sonographers, they tell stories about seeing something that they think might be a marker for a fatal anomaly but they don't know, they don't actually know what it means. They don't know if it's a risk factor because they just don't know whether it's actually part of normal development or whether it's an indication of something serious.

So, there's a lot of uncertainty in obstetric ultrasound and related to this question of the management of risk. So there's a very strong desire on the part of sonographers and obstetricians to get clear pictures or what they call beautiful pictures, which means technically very clear, because that helps you say what is wrong and what isn't. But at the same time some images or some indications of things just elude certainty because they just don't know what they even mean. So there's a lot of uncertainty in that.

On of the things that I want to emphasize in talking about normalization is that normalization itself isn't geared toward the eradication of the normal – of the abnormal, sorry. It's geared toward the management of the abnormal and the identification of it but normalization in and of itself does not – in Foucault's formulation at least - doesn't require that the abnormal be eliminated. It doesn't actually determine what we do with the abnormal. What's interesting then is this question of what Eva Kittay calls the desire for the normal. So we have this really strong desire for the normal. And I'm not sure where that comes from, we can talk where – what might be the kind of drivers of this desire for the



normal, but I think there's a very strong kind of affective commitment to ideas of normal – of the normal. So it's that desire for the normal that actually kind of leads to decisions around termination of pregnancy, that drives the elimination of the abnormal, if you like.

Now what I think is really interesting in relation to ultrasound and the context of ultrasound testing in Australia, is that this desire for the normal is channeled through ideas of choice. Now as we said before what we're interested in is choice and this Apparatus of Choice, and so there's a very strong emphasis on choice but somehow the decisions made in that space of choice are often decisions that reflect a desire for the normal. So this desire for the normal somehow gets channeled through choice.

So I think here we see that there's a very strong and very interesting kind of connection between an emotional attachment to the normal, various moral principles or ethical principles around patient choice and autonomy and at the same time this kind of – this process of normalization that happens through ultrasound screening. So that's where I think we get a very interesting mix of things going on. And it seems to me that there's a lot more theoretical and empirical work to be done just teasing out that particular nexus of emotional – or emotion ethics and normalization.

3. Apparatus of choice

I realize I'm actually kind of talking a lot of what we found out in this study without actually telling you much about it. So let me back step a little and tell you a bit more about the study we did. So as I said this was a study funded through the Australian research council and undertaken by my colleague Niamh Stephenson and with some research assistants along the way. It was primarily a qualitative and philosophical study of obstetric ultrasound. I should

say that hasn't finished. We've finished the quantitative data gathering but the philosophical part, my responsibility, is still very much ongoing, partly because I have become obsessed with fetuses, you might say. I find the fetus the – and questions around the fetus very, very interesting as really there are a large number of bioethical questions around the fetus and around ultrasound that really just have not been discussed at all.

So I have become very interested in that, so it's ongoing.

In any case, our interviewees were recruited from both private clinics and some public hospital settings. We undertook semi-structured interviews as well as observations of ultrasound scans. In total 26 women were interviewed, either after their 12-week nuchal translucency scan or after the 20-week morphology scan in a couple of cases after both when women agreed to do that.

We also then went on to interview 27 professionals involved in the provision of ultrasound in obstetric care. This included about 16 sonographers and then the rest made up of obstetricians, genetic counselors and disability advocates. The primary aim of that project was to address the question of how ultrasound impacts on questions about the moral status of the fetus. So how people thought about the fetus, how they felt about it and how they kind of approached questions or thinking about termination. As it happened, I mean, none of the women that we interviewed were actually – we didn't – we don't know if they had terminations, they may well have. So we weren't interviewing after terminations which would be a really interesting project to do. But thinking about or asking about their kind of approach to ultrasound testing, what they thought was going to happen in – what they wanted from it and so on.

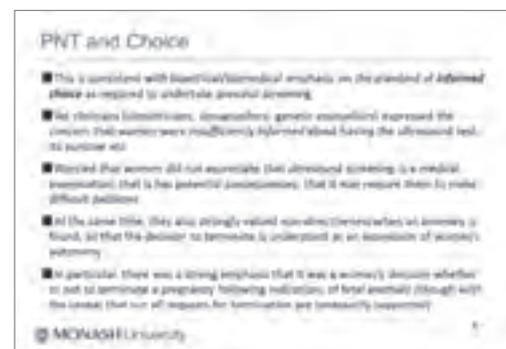
Now what's interesting is that we didn't actually



set out to ask people about choice in that study. But in the transcripts it very quickly became evident that, that was the kind of principle organizing idea, if you like. The way in which people thought about ultrasound and prenatal testing was through the idea of individual choice. It's in all sets of transcripts, whether its women or professionals, there's a very strong emphasis on choice. So I wanted to then think about what this emphasis on choice was doing. Now it's not surprising in some ways that choice was so heavily emphasized. I mean it's -- this emphasis is very consistent with both a kind of broader political context of liberal democracy and of liberalism more generally, where there is a emphasis on individual choice, but also is consistent with the bioethical and biomedical emphasis on informed choice and informed consent. So that's what we see in a lot of medical or biomedical practice is a – is this kind of emphasis on choice.

At the same time though that while there was strong emphasis on choice, one of the things that became very clear very quickly is that clinicians and other professionals were very worried that women weren't sufficiently informed when they were making their decisions. So there was a very strong emphasis on women being insufficiently informed and this is tied up with the idea that they weren't making proper choices or properly framed choices, genuine choices.

In particular, they were worried that women didn't appreciate that ultrasound is a medical examination. So this is one of the – it was a kind of very interesting moment in the study when one of the people who was helping – or one of the clinicians who was helping us recruit women for the study was complaining vociferously to us about how women were coming in without any understanding that this was a medical test. They would come in thinking that this was a social occasion, they would bring their families. It was really – for him it was a really big



worry that women just didn't understand that this was a medical exam – a medical test. And this worry was then repeated a number of different times and in different ways throughout the interviews.

So there was a concern that women weren't informed, they didn't appreciate that ultrasound screening is a medical examination, that it has potential consequences that they need to make decisions about and those decisions might be quite difficult. So that having an ultrasound scan might lead to bad news. Or bad news that women had to make decisions about. The clinicians often felt that women just didn't know enough about that. At the same time, following the ultrasound tests, the clinicians also very strongly valued non-directiveness. I mean this is very consistent with what we would see in bioethics I think. So they strongly valued non-directiveness when an anomaly was found. So then it's just about information provision, such that the decision to terminate was understood or could be understood as an expression of women's autonomy. So that was very important for them that this decision could be understood as an expression of a woman's autonomy or her choice.

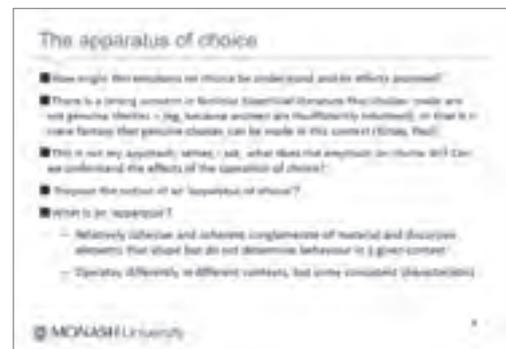
In particular, there was a strong emphasis that it was a woman's decision whether or not to terminate any pregnancy following an indication of fetal anomaly, with the caveat or with the limitation that not all requests for termination would be allowed. So even if – even in a legal context where it might be legally permitted, there were some occasions when the hospital, in the public system in particular, would say no, that they wouldn't perform a termination or they would be worried about performing a termination for that particular reason.

One case that I've written about in another paper is a case where a woman had – at her 18-week scan – her fetus was discovered to be missing its left hand and – this was a public hospital scan – when it was

confirmed that the fetus was missing its left hand, she wanted to have a termination. The hospital that – the doctors she was dealing with were very uncomfortable performing it and this was at 18 weeks, very close to the 20-week mark which in New South Wales (where this case was) is a kind of ‘moral’ cut off point, in a way. It’s not legally – legally they could have performed the termination but they were very uncomfortable with doing it at that stage of development for that patient.

And there would be other cases of – I’ve heard cases of termination for things like cleft palate or cleft lip, where the hospital ethics committee would be very uncomfortable allowing a termination for those reasons. But in a number of states at least - abortion law in Australia is confusing because it varies by state, so every state in Australia has a different abortion law, and none of them are consistent – this would be legally possible. But even if its legal sometimes there are circumstances when the doctors don’t necessarily want to do.

So, okay, so now we're getting onto the question of the Apparatus of Choice and how we might like to think about that. So my question that is what – how might this emphasis on choice actually be thought about and how might we understand the effects of that emphasis on choice. Now interestingly there is a strong concern in feminist bioethical literature that choices made about prenatal testing can be understood as genuine choices. This is actually a question of whether women are sufficiently informed and so on. So there's a lot of – quite a number of papers on whether prenatal testing and decisions in various context actually count as genuine choices. There's also an argument that says, well, in fact there can never be genuine choices because we just don't know what a life with a disabled child will be about – will be like. So there's just no way that women can be making informed choices because it's



not possible to be informed about what your life will be like with a disabled child. So disability of the kids per se will in fact – I mean people could be better informed at least than what they are.

In any case I'm not going to take that approach. I'm not going to question whether it's genuine choice or not. I think that's a very difficult question and probably impossible to actually answer in some ways. Instead I'm going to focus on this question of what the emphasis on choice actually does and how can we understand the effects of this operation of choice. So I'm going to propose the notion of an Apparatus of Choice. And that obviously raises the question of what an apparatus actually is.

So again I'm drawing on Michel Foucault's work and his idea of an apparatus with this *dispositif* which he develops in some detail – well, not in a great amount of detail I must admit, though he gives an outline and I'm going to kind of use that outline. So just to give you an idea of what I mean by an apparatus I would say that's it's a relatively cohesive and coherent conglomeration of material and discursive element that shape but don't determine behavior in any given context, so to relatively cohesive bit of a material discursive circumstances or techniques. And I think one thing to keep in mind is that an apparatus operates differently in different contexts but it will always have some consistent characteristics such that we can identify it as a particular apparatus as opposed to another.

So Foucault suggests that there are three things that we can focus on to trace or outline an apparatus and he suggests so that the three axes of an apparatus could be subjectivity, knowledge and normativity. So we can look at those kinds of elements to get a picture or an outline of an apparatus, and in particular, in this case an Apparatus of Choice. So in relation to the apparatus of choice we'll just quickly run through what those



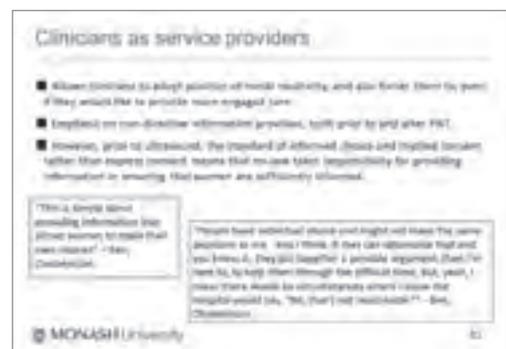
three things might suggest about the Apparatus of Choice. So in relation to subjectivity, I think the apparatus of choice presupposes subjects capable not only of making choices but of making rationally justifiable choices. So it's a question of rational moral agents – this becomes very important, being sufficiently informed, being sufficiently rational to make certain kinds of choices as opposed to others. So we shouldn't just be making choices randomly based on our emotions and so on, they should be rationally justifiable choices.

In terms of the axis of knowledge, in relation to the Apparatus of Choice, as I've emphasized there's a very strong emphasis on this question of being informed. And in the Apparatus of Choice this primarily means in terms of being informed in terms of the medical view of an anomaly. So trying to understand the medical information about any particular diagnosis or anomaly, there's an emphasis on the delivery of that information, there's not actually that much discussion about, for instance, the life stories of people who have raised disabled children, which for the disability advocates was quite a problem. Actually, in this question of who has what knowledge in the Apparatus of Choice, it's interesting that certain kinds of knowledge was seen as important by some people, while others would see it as not important or just not registered at all. And as I said before there's a very strong question about the management of uncertainty and risk in the Apparatus of Choice. So there's lots of discussion about the management of uncertainty and questions of epistemological uncertainty, knowing what's what, knowing what the truth of the matter is in relation to an ultrasound finding and so on. So my colleague Niamh Stephenson has written an interesting paper on the ambiguity of ultrasound images and this question of how we deal with the question of uncertainty.

Now third is the axis of normativity. And here I think, in the Apparatus of Choice we can see that choices are understood as needing to be free. They're supposed to be free choices. And that is meant to be or that is understood as meaning not being impeded by others. So we're operating with liberal notions of freedom and autonomy as independence and so on and there's a very strong individualistic focus. It's a question of individuals or particular individuals making rational choices based on sufficient information and not being overly influenced by others in those choices. So that's the kind of thing we're talking about.

So then what does this Apparatus of Choice do? Well, I'm going to run through three particular groups of people in relation to the Apparatus of Choice. The first one of these is clinicians. And this is very interesting actually or I think is very interesting. Because, a lot of the clinicians we talked to were actually very, very reflective about how this emphasis on choice actually affects their work. Not all of them, I must admit, but a number of them were very, very reflective about how choice actually affects their kind of positioning. And basically I would argue in relation to clinicians that the Apparatus of Choice allows clinicians to adopt a position of moral neutrality. It allows them to adopt the position of saying it's your decision, you make that decision, you carry that responsibility. Now for some clinicians that was good. They were happy to see themselves in this way, and I quote, "We are just service providers." That's the understanding of some clinicians, is that their job is to provide a service. What happens on the basis of that service, there service being ultrasound testing, what happens on the basis of that is up to someone else. It's not their responsibility.

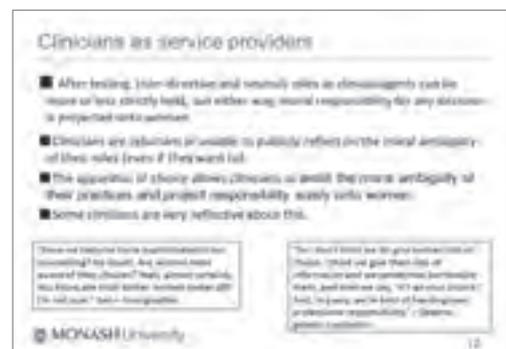
But others were somewhat bothered by that kind of approach, and they thought that in fact this was a way of kind of giving over or not taking on, or



avoiding their moral responsibility. Their responsibility as carers –of medical carers to actually help women make those decisions in various ways. So some people saw just – their job as just a matter of service provision and this emphasis on choice allows them to adopt a position of moral neutrality and others saw that as problematic, that in fact, it forced them into a position of neutrality and moral abdication when in fact they would like to be more engaged.

Now one of the other things that came through very strongly was that clinicians were either reluctant or unable to publicly reflect on the moral ambiguity of their roles, even if they wanted to sometimes. So some clinicians had actually tried to publicly engage with this question of the moral ambiguity of prenatal testing, they had written to sort of parenting websites and so on, but their writing had not been published. But a lot of them just really didn't want to have this conversation at all. In particular they don't want to have a conversation about prenatal testing and its moral ambiguity in Australia because that would entail having a conversation about abortion and abortion is just so politically difficult that no one wants to open that box. That's essentially what it's about. No one wants to kind of provoke a public debate about abortion in Australia, because of the way that could go – it might make things much worse for clinicians if there is such a debate.

So in general, then, I would argue that the Apparatus of Choice allows clinicians to avoid the moral ambiguity of their practice and project responsibility for decision making around prenatal testing and termination onto women. So they handover all the moral responsibility for prenatal testing decisions and termination decisions onto women, so women have to carry that burden of moral responsibility. So I've just put up a couple of quotes there from some of the more reflective



obstetricians and clinicians when they suggest that in fact things have not got better necessarily with ultrasound scanning, that in fact, it's just made it more difficult for women.

So the next group is women. So the question of how women fit into the Apparatus of Choice, I think, is really important. So I argue that in the Apparatus of Choice women are cast as responsible moral agents capable of informed decision making and who bear primary culpability for their actions. That seems to me pretty kind of uncontroversial and pretty standard that women – pregnant women - are seen as the primary moral agents for their decision making in relation to prenatal testing and termination and are also the ones who bear primary culpability for that – for that decision or their actions following that decision.

At the same time though some women were actually understood, it seems to me, as being fundamentally irresponsible, both culpable but incapable of informed decision making because they wouldn't or couldn't understand the significance of prenatal testing as a medical examination for instance. But they were nevertheless seen as being culpable for that failure.

So the two groups of women who particularly fell into this categorization as being – of being fundamentally ir-responsible - were women who were insufficiently informed about the test, the ultrasound test to begin with, they just didn't understand what it was about, or women who were insufficiently respectful of the medical context of that test. So they – those two groups of women were seen as being irresponsible in some way or another. And these are different groups of people actually, they break down differently in some ways. So often the first group of people, the ones who were just insufficiently informed might be women who don't speak English as a first language, for instance.



So they are necessarily irresponsible, in a way, and I'll say more about that in a moment. But the other group of women who were kind of just insufficiently respectful would be women – the sonographers, in particular, complained about these women. One sonographer in particular complained about these kinds of women. They would be women who came into the test with their friends, for instance, and just didn't engage at all. They were much more interested in talking about their shopping expedition than seeing pictures of their baby on the screen. So they were just not really kind of tuned into or switched on to the – to what was going on in terms of a medical test. It was all – for them it was much more kind of a social occasion to see – for everyone to see the fetus or wanted their family to see the fetus or really they were just kind of very blasé about the whole process.

So as I said, elaborating on the first group of women who were just seen as being fundamentally irresponsible, as I said there's a very strong emphasis on informed choice or the information provision. I should've emphasized this more beforehand. But what's interesting about the fact that there is no – because there is no consent process for ultrasound in Australia, no one takes responsibility for actually providing that information. Okay? So no one – even though there's a very strong emphasis on individual – on informed choice, no one takes responsibility for actually providing the information before women have an ultrasound test.

So the person who people think – or some clinicians think - should provide information is the general practitioner or the family doctor who refers a woman to the ultrasound service. But they're very busy. They have 15 minutes in which to do all the work that they have to do and there's no set guide for the kind of information that they should provide because there's no consent process. So they don't

tend to actually provide women with the information about ultrasound beyond saying that it's a test for Down syndrome. Often the conversation is along the lines of – this is a test for Down syndrome, most women have this test, do you want to have it? That would be the kind of level of information provision.

So the main source of information for women is actually the websites of the clinics themselves. So many of the clinics actually have quite informative websites about what ultrasound examinations will actually tell them about their baby. And that's great, if you read English and have access to the Internet, okay. But if you don't read English and you – or you don't have easy access to the Internet then there's just no way you can actually be the kind of informed person or informed moral agent that the Apparatus of Choice is requiring you to be. So that's why I think it casts some women as fundamentally irresponsible. In that context, they're failing to be responsible – the kind of responsible agents that they're supposed to be, but at the same time they are still seen as culpable for that, even though there are circumstances that they just couldn't be responsible in, if you like. So they're both irresponsible and culpable.

So that's I think – that's the very problematic end of the emphasis on choice I think. Okay, so, women – so a few further aspects of the characterization of women as moral agents. So as I've emphasized there's a very strong emphasis on the control of information. But the lack of consent process means women are made responsible for their own condition of being informed and there are problems with that.

At the same time there's also other aspects that come out in the comments of sonographers in particular. So there's a question of a woman's control over her body. So the ideal woman coming into an ultrasound in the transcripts from sonographers is thin but not too thin, her bladder is full but not too full,



her baby is active but not too active, if it's too active they can't get good images, but it's not active enough then they kind of worry about whether it's okay, and a woman has to come back and it takes ages and so on.

They need the baby to move in various ways, they need it to roll over and present its face to them, for instance, and if it doesn't do that then there are technical problems and they have to send women away and she has to come back and so on. So ideally they want a patient who comes in with their baby facing upwards, who will roll over at the appropriate moments so they can scan its spine and then be on their way. So that's their ideal woman.

She's thin because obese patients are much harder to get clear images of from, but sometimes a thin – a very thin woman is difficult as well because they just can't tell for instance whether – if its falling outside the measurements for fetal growth they don't know whether that means that's just because she's really thin or whether there's something wrong with the baby. So too thin is not so great either.

But one of the things that I found particularly interesting was this emphasis on the control of a woman's emotion. So as I said – as I suggested for many sonographers the ideal woman having an ultrasound is concerned but not anxious. So they often complained about the super anxious women who came and there's just nothing you can do to reassure them and they're constantly asking questions for reassurance and so on.

These were not women that sonographers liked very much because it meant they were being constantly interrupted and couldn't get their job done efficiently. But at the same time they want them to be engaged but not demanding, they want them to not come in and just be kind of blasé and unconcerned about the fetus, they want them to be concerned about their fetus but not anxious. So –

there's a kind of tight line that women have to walk in terms of controlling their emotions.

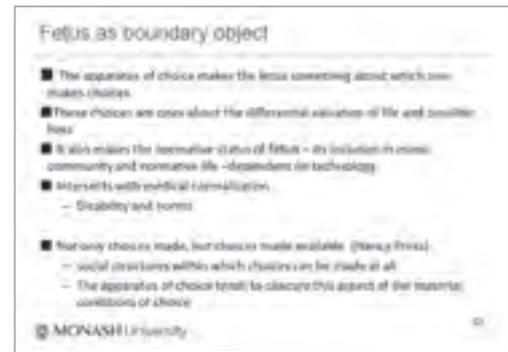
So one sonographer, was particularly talkative about the kind of ideal patient and she was saying that the super anxious ones are really difficult because you just can't get them to calm down and they're constantly asking for reassurance, and no matter what you tell them they just don't stop. And then the other ones that she said that women who come in with their girlfriends from their shopping expedition and they're a nightmare, because they just kind of talk to each other and they don't engage with the sonographer at all. So for her they were her least favorite women. And I think the control of emotion links back to this question of rationally justifiable decision. So it's about being a rational agent that you sometimes have a control over your emotions and so on.

One of the other interesting things that comes out in the interviews around the control of emotion is a question of the relation between the sonographer and woman and the delivery of information. So one of the difficult problems for sonographers is when – if they see some kind of indication at the beginning of the test that something's just not quite right, one of the difficulties is knowing what to do about that. So you don't – they don't want to provide information to women too early and upset them, because if a woman starts crying they can't get very good images because she's moving too much. So you don't want to – a woman who is weeping because you can't get good images. At the same time they feel it's bad to just go through the whole scan saying, "Yes, it's all fine. It's all okay," and then get to the end of the scan and say, "Well actually, it's not so good. There's some indications of problems here, because that seems a bit deceitful or duplicitous So, there's a real problem for sonographers how to control a woman's emotion as well and to control that kind of communication

between them and women patient's being scanned

So the third group, the fetus – the fetus itself. What I think the apparatus of choice does to fetuses is turn them into boundary objects. So 'boundary object' is a term that I'm taking from an interesting article by Claire Williams. And it's basically suggesting that it's something that kind of sits on the border of the moral community, if you like. That's my understanding of it. That it's something that is on the boundary of the under – our understanding of what's a person, what's a human. Some fetuses will become persons and some won't. So it's an object that we make decisions about, that we make choices about. There's nothing necessarily inherent to a fetus that will determine that it's a person or even if they were it doesn't – that inherent characteristic - doesn't determine its fate. It's something about which we can make choices, certain kinds of choices. And in my view these choices are choices about the differential valuation of certain kinds of lives as opposed to others. So it's an understanding of which life – it's a question about which lives matter. I mean that's the blunt way of putting it - how much do we value some lives as opposed to others? that's essentially what that question comes down to I think.

So the other really interesting thing is that it makes this question of what lives matter and the normative status of the fetus, the question of whether it kind of sits in moral community or not, it actually makes those questions dependent on the technology of ultrasound. So ultrasound actually then comes to play this very, very important and interesting role in the constitution of moral community or the constitution of the category of the person. Ultrasound is very, very deeply embedded or intertwined in this kind of in the production of persons, if you like. So that's what I think is really interesting about ultrasound or one of the things that I think is really interesting. And obviously this

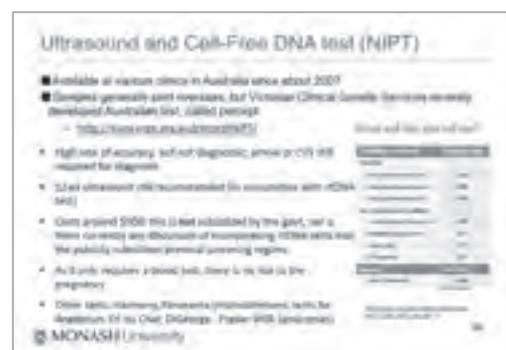


intersects with questions about disability and how we think about disability more broadly in any given social context. And one thing to emphasize then is that – this is a point made by Nancy Press in a very interesting little article - that what matters here is not only the choices made but the choices that are actually made available to women. What kinds of choices actually even register as rational decisions? What choices are possible?

So sometimes, for instance, women will make a decision to continue a pregnancy even in the face of information about a severe fetal anomaly. For many clinicians that decision does not count as a rational decision. They just can't understand that as a decision that someone can rationally make. And I think that is about – this kind of question of the social structures of choice, there's something to be explored further there about the kind of social structures that make some decisions possible and not others. And I think the Apparatus of Choice tends to obscure this particular, kind of, working or structuration of choice by making it all about individual choice or individuals.

4. Choice and consent

Okay. So I think I have now covered the discussion of the Apparatus of Choice. But I want to turn briefly to the emergence or an introduction of cell-free fetal DNA testing in Australia. Because as I said in the beginning, this I think is putting pressure on these questions about choice and consent. So we'll talk – I'll talk briefly about that. So ultrasound has been the primary non-invasive screening test in Australia for a long time – for quite some time. Until I think late 2012 actually -- its not entirely clear but late 2012 I think was when NIPT was actually first used in Australia. And initially late 2012. And initially samples were collected in Australia and then sent back to the USA. Okay? So all samples collected were



sent to the USA for actual testing. But recently the Victorian Clinical Genetics Services has actually developed its own tests, so the actual testing can be done in Australia, and that test is called 'percept'. So there's – you probably know there's various – there's a range of names for this test.

I think the common one is Harmony, and Australia – the Victorian Clinical Genetics Services is calling their test 'percept'. Now what's interesting about this test is its very high rate of accuracy, especially for Down syndrome, which is its greatest appeal. So it has a greater than 99%. It's about 99.7% I think or 99.6% rate of accuracy for Down syndrome. But at the same time it's still not a diagnostic test. It doesn't tell you definitively whether your child actually has Down syndrome or not or another trisomy conditions. So what this test actually tests for is the three trisomy conditions, trisomy 21, 18 and 13. It also can be used to test for Turner syndrome, which is a sex chromosome problem and it can also tell you whether your child is going to be a boy or a girl. So it's not a very vast range of things that its used to test for. I think that's five or six things and that's all.

So it has a high rate of accuracy though, especially for the trisomy conditions. Given this, the real question that is emerging in or has emerged in Australia amongst clinicians is just how the test should actually sit within the ultrasound scanning regime. They still, for the most part, recommend having a 12-week ultrasound because the ultrasound does other kinds of things as well as test for Down syndrome. So it can tell for instance whether some structural defects will be evident at the 12-week mark, as I said before, there's more evidence that ultrasound at 12 weeks can be used to test for preeclampsia and so on. And so that ultrasound is still strongly recommended in Australia.

So it's not as if NIPT will actually replace the 12-week ultrasound. That's not going to happen. And

especially not since it costs about – and still costs about \$500 in Australia and that is not subsidized by Medicare at all. So that means that a woman, if she wants to have NIPT, she will have to pay that money herself. And there's not currently any discussion either about including NIPT in the subsidized prenatal testing regime so as I said she will have to pay that cost.

The other benefit, of course, because it's only a blood test it also involves no other – no dangers to the pregnancy, which is its great advantage of amnio and CVS. But again, if you want certainty, you still are required to have amnio and CVS if you have a particularly high risk factor for any conditions. And CVS and amnio are still very useful because they test for a wider range of things than you could get NIPT testing for. So again if a woman has a nuchal translucency scan, has a high risk from that for Down syndrome the question then emerges is well, should she go and have an NIPT test or should she just go straight to amnio?

Now it may be that she could just go to NIPT and she would then be told that in fact there's a – it's not very likely that her fetus will have Down syndrome. Or if she gets a high risk then she will still have to go to amnio anyway to get a definitive diagnosis. But if she only goes to NIPT there may be other conditions that are then not being tested for, that would show up in an amnio. So she may decide even then that she has to have an amnio to really get a definitive diagnosis to rule out other kinds of defects that might be generating the risk factor in the first place.

So it's very difficult to know which test is actually beneficial in any given circumstance. So there's a real question about just how it will even be incorporated and how it should be. And at the same time there are other tests as well that will test for various other conditions, microarray testing, which will test for things like Angelman syndrome and so on,

which again are not tested for in NIPT. So there's a real question there.

But what I find interesting is the fact that while NIPT requires patient consent, and the standards of informed consent are supposed to be applied – I say ‘supposed to be’ because they are in principle applied, but we don’t know quite what happens in practice – the same kind of standard doesn’t hold for ultrasound testing even though it is also a non-invasive testing technology. So one might imagine that two non-invasive testing or screening technologies have the same kind of standards for informed consent or informed choice. But in fact we have a contradiction whereby one requires informed consent and one requires simply informed choice. And as far as I can tell, there’s no principled difference that justifies this kind of contradiction between fetal DNA testing and ultrasound. Instead it seems to me it’s just a historical artifact of the ways in which ultrasound itself was introduced, whereby that just came into Australia – was introduced in Australia by first one person coming from the U.K., introducing it in his clinic and then it kind of took off. So that developed in a very ad hoc way. NIPT has also been introduced in Australia in a very ad hoc way, and it’s just because they are kind of not really under any kind of national standard or national scrutiny that these systems have developed, it seems to me.

So it seems to me that there’s a real question about whether Australia should actually have a more coherent system of choice or consent for non-invasive testing, and the question that I’ll finish on is whether having an informed consent process for ultrasound would actually help to ameliorate some of the more negative effects of the Apparatus of Choice such as the casting of some women as fundamentally irresponsible because they can’t or won’t take the test seriously as a medical test.

They can’t access the information; they either can



access it but won't and so on. And so it's that question of whether having a consent process will actually mean that someone takes responsibility for providing information, the information that would actually be necessary for making informed choices in relation to ultrasound or whether it really – it just won't have that effect. I mean there's – I think there's an interesting question there about whether we should introduce some kind of consent process for ultrasound or whether we should get rid of the consent process for NIPT.

So I'm going to finish on that note and ask you to tell me about the context in Japan.



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Her recent publications and articles are as follows:

Mills, C. 2015. *Biopolitics: A Critical Introduction*. Under contract with Routledge; MS to be submitted December 2015.

Mills, C. 2011. *Futures of Reproduction: Bioethics and Biopolitics*, Springer.

Mills, C. 2015. "The case of the missing hand; or, Gender, disability and bodily norms in selective termination".

Special issue, 'New conversations in feminist disability studies', *Hypatia: A journal of feminist philosophy*, 30(1).

Mills, C. 2014. "Making Fetal Persons: Fetal homicide, ultrasound and the normative significance of birth", Special issue on international perspectives on birth, *philoSOPHIA* journal, 4(1): 88-107.