

IGS Project Series No. 1

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IGS Seminar

## Choice and Consent in Prenatal Testing

Institute for Gender Studies

Research Organization for the Promotion of Global Women's Leadership

Ochanomizu University

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## **Seminar Details**

### **【Date/Time】**

November 18<sup>th</sup>, 2015, 18:15~20:45

### **【Seminar Venue】**

Room #408, Graduate School of Humanities & Science Building  
Ochanomizu University

### **【Speakers】**

Catherine Mills, Ph.D (Monash University)

“Choice and Consent in Prenatal Testing in Australia”

Azumi Tsuge, Ph.D (Meiji Gakuin University)

“What Do Women Want to Choose in Prenatal Testing in Japan?”

### **【Commentator】**

Marcelo de Alcantara, Ph.D(Ochanomizu University)

“Prenatal Testing from a Legal Perspective”

### **【Coordinator】**

Yukari Semba, Ph.D (IGS, Ochanomizu University)

### **【Organizer】**

Institute for Gender Studies, Ochanomizu University

### **【Number of Participants】**

9

## Foreword

Dr. Mills has many publications related to the issues of abnormal fetuses and abortion, prenatal testing, and women's reproductive autonomy. In Japan, non-invasive prenatal screening tests (NIPS) were introduced in April 2013. NIPS consists of cell-free fetal DNA screening. Before the clinical use of NIPS was introduced in Japan, there were many debates about its appropriateness, specifically regarding whether it might promote the selective abortion of potentially abnormal fetuses. So we decided to discuss on the issue in this seminar, and asked Dr. Mills to give a presentation titled "Choice and Consent in Prenatal Testing." We also invited Professor Azumi Tsuge (Meiji Gakuin University) to provide her knowledge about prenatal testing in Japan. We asked Professor Marcelo de Alcantra (Ochanomizu University) to deliver comments from a legal perspective.

In the field of reproductive medicine, women's reproductive choice and moral responsibility will receive more and more attention because of the increase in pregnancies of women with advanced maternal age in Japan. We would like to keep in touch with Dr. Mills and work with her on these issues in some way in the future.

we were able to enjoy a thorough discussion even though the number of seminar participants was not large. Please read the following pages of this report for details of each presentation, comments, and so forth.

Dr. Ryoko Ishikawa (Ritsumeikan University) made the seminar possible by introducing Dr. Mills to us. We appreciate her support towards our institute.

On a more personal note, I joined the Institute for Gender Studies in the middle of September, 2015. The experience of arranging a seminar like this one was new to me, but my colleagues at the institute provided me with all of the support I needed, for which I am deeply appreciative.

March, 2016

Yukari Semba, Ph.D.  
Project Research Fellow, IGS, Ochanomizu University

## セミナーを開催して

2015年7月、同年11月に来日予定であったモナシュ大学（オーストラリア）のキャサリン・ミルズ氏を、立命館大学准教授の石川涼子氏（元 IGS アソシエイトフェロー）からご紹介いただき、ジェンダー研究所にて、ミルズ氏を迎えての生殖医療とジェンダーをテーマにした英語セミナーを開催することが決定した。

ミルズ氏は、胎児の障害と中絶、リプロダクティブ・オートノミー等に関連する論文を多く発表し、出生前検査における倫理的側面からの研究も勢力的にされている。日本でも2013年4月から新型出生前検査（NIPT）が実施されるようになり、NIPTの導入をめぐる賛否両方の声が聞かれた。そこで、今回のセミナーでは出生前検査と選択的中絶の問題をとりあげることとし、ミルズ氏には「Choice and Consent in Prenatal Testing（出生前検査における選択と同意）」というタイトルで報告していただくことになった。そしてこれを本セミナーのタイトルにした。ミルズ氏のほかに、日本の出生前検査についての聞き取り研究調査を続けられ、諸外国の出生前検査についても多くの情報をお持ちの明治学院大学の柘植あづみ氏をお招きし、日本の状況についてご報告いただくことにした。合わせて、生殖医療の法学的側面に造詣の深い、お茶の水女子大学のマルセロ・デ・アウカンタラ氏にコメントをお願いした。

当日は夜のセミナーであり、また雨も降っていたため、出席者は9名と少なかったが、少人数で充実した討論が出来たと思われる。セミナーの詳細については、このあとに続く報告をご覧ください。

今後も出生前検査のみならず、多くの生殖をめぐる医療分野で、女性の選択と道徳的責任が重要な問題となるだろう。ミルズ氏とは今後もさまざまな形で情報交換を続けていきたいと考えている。

個人的なことながら、2015年の9月にジェンダー研究所に特任リサーチフェローとして着任した。この企画は着任してすぐに担当したということもあり、至らない点多々あったと思うが、IGSのスタッフから様々な支援を得て無事開催できたことをうれしく思う。

IGS 特任リサーチフェロー 仙波由加里  
2016年3月

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# Choice and Consent in Prenatal Testing in Australia

**Catherine Mills, Ph.D.**  
Monash University



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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 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.

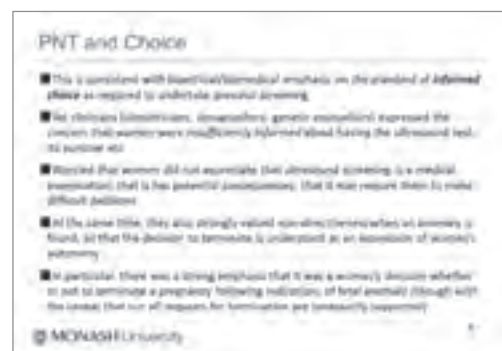
Now what's interesting is that we didn't actually



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.

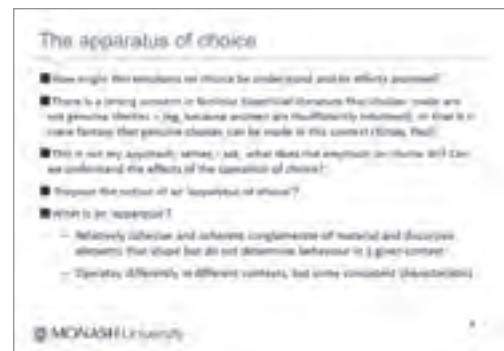
One case that I've written about in another paper is a case where a woman had – at her 18-week scan – her fetus was discovered to be missing its left hand and – this was a public hospital scan – when it was



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.

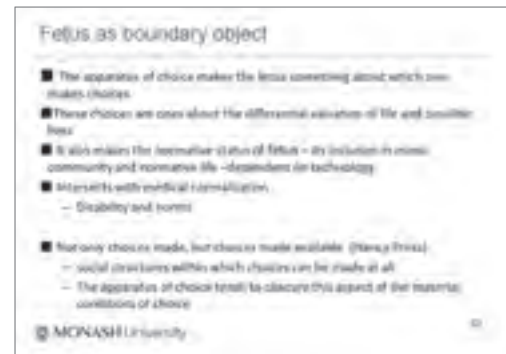
So one sonographer, was particularly talkative about the kind of ideal patient and she was saying that the super anxious ones are really difficult because you just can't get them to calm down and they're constantly asking for reassurance, and no matter what you tell them they just don't stop. And then 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

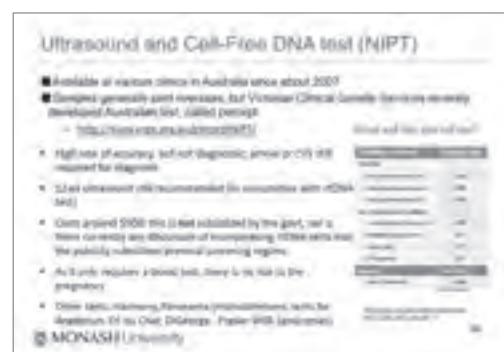


intersects with questions about disability and how we think about disability more broadly in any given social context. And one thing to emphasize then is that – this is a point made by Nancy Press in a very interesting little article - that what matters here is not only the choices made but the choices 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.



### **Catherine Mills**

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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.





# What Do Women Want to Choose in Prenatal Testing in Japan?

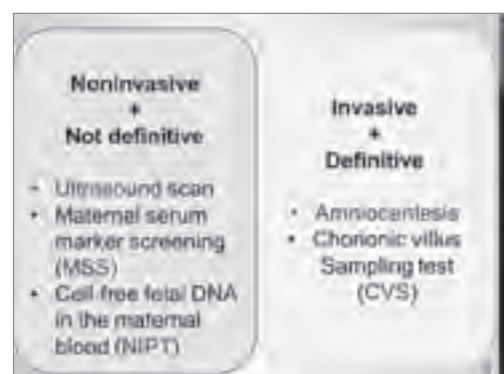
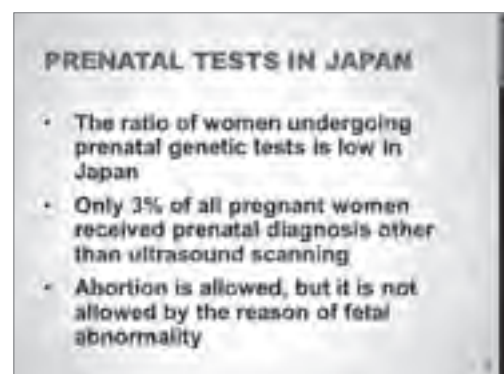
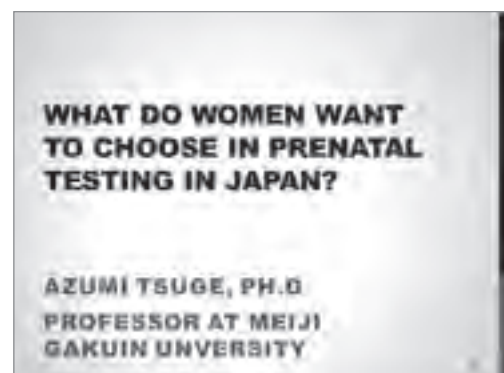


**Azumi Tsuge, Ph.D.**  
Professor, Meiji Gakuin University

I am a medical anthropologist. I mainly study interrelation New Reproductive Technologies and Society. Today I will give you information on prenatal testing in Japan, and I would like to show the social background that is relevant to Japanese unique history with regard to prenatal testing.

## Japanese Situation Regarding Prenatal Testing

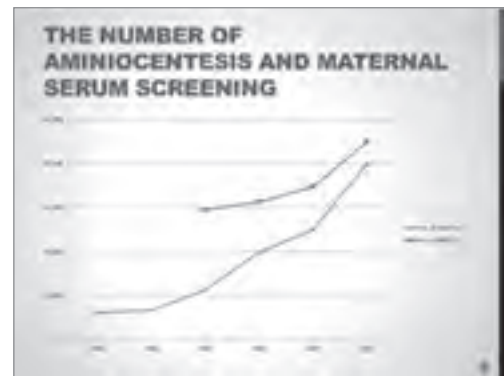
The ratio of women undergoing prenatal tests other than ultrasound scanning in Japan is relatively lower than in any other medically advanced country. According to Sato, who was one of the leading specialists on prenatal testing in Japan in the 1990s, he reported that the incidence of maternal serum screening conducted in the United States, the US is about 167 times that of Japan, and the frequency of amniocentesis in Germany was 10 times that of Japan in 1999 (Sato 1999). Another research report showed that only 3% of all pregnant females received prenatal diagnosis based upon maternal serum marker screenings or chromosome analysis in Japan (Sasaki 2011). On the other hand, the fact is that many



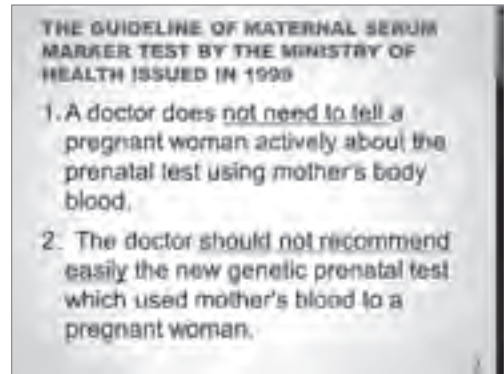
clinics and hospitals have been practicing ultrasound scanning and abortion procedures in Japan. We usually use ultrasound scan, which is not recognized as a prenatal testing is. And maternal serum marker screening and cell-free fetal DNA in the maternal blood are also available though not many pregnant women use them. Cell-free fetal-DNA-based prenatal testing, so called NIPT started in 2013 in Japan. These are said to be non-invasive and are not considered definitive test. Amniocentesis and chorionic villus sampling are said to be invasive tests.

Total numbers of amniocentesis and maternal serum screening in Japan increased between 1987 and 2012. However their total incidence is only 3% of all pregnant women. But in Japan, lately the government has emphasized the declining birth rate. And the number of live births by age group, is shown in this figure. The number of live births is declining. But the subtotal for maternal age over 35 years is increasing.

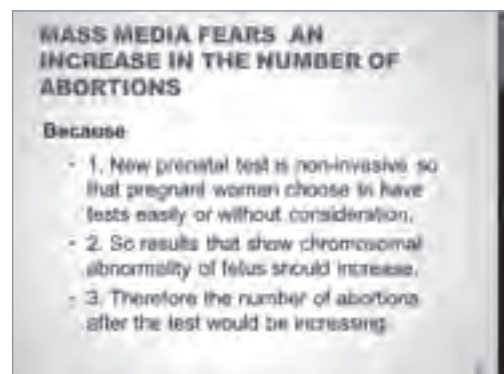
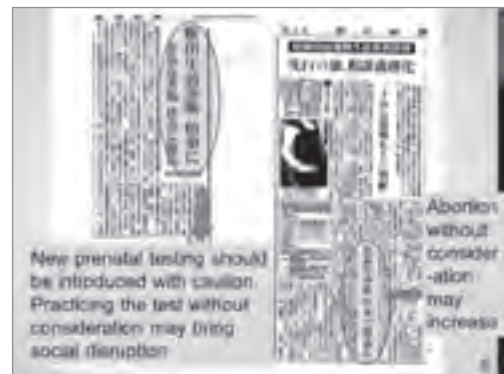
The Japanese Government and the Japan Society of Obstetrics and Gynecology (JSOG-Japanese OB/GYN Association) have emphasized that those are serious issues for Japan because they are related to the increasing the number of infertile women or couples, and may be increasing the ratio of fetus with chromosomal abnormality. The ratio of live birth by women over 35 years old increases from 1950 to 2010. Now you see why the Japanese government and the OB/GYN doctors worry about that from these figures.



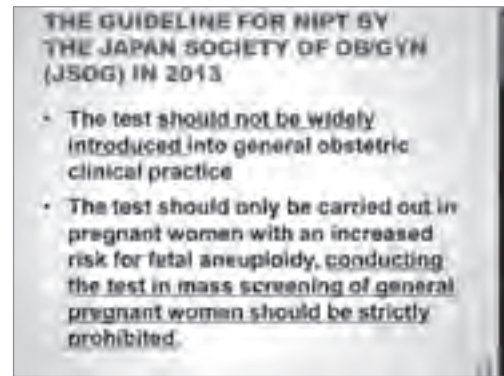
As I already said, Japan has a unique condition and situation regarding prenatal testing. For example, the Expert Committee of Ministry of Health on Prenatal Diagnoses issued the guidelines regarding maternal serum marker test in 1999. It said that a doctor doesn't need to tell a pregnant woman on his own initiative about the prenatal test using mother's body blood. Whenever I show this guideline at a seminar in North America, people always ask me if it is my typo. Then I said, "no, no, no, it's correct. A doctor doesn't need to tell a pregnant woman about the maternal serum marker test."



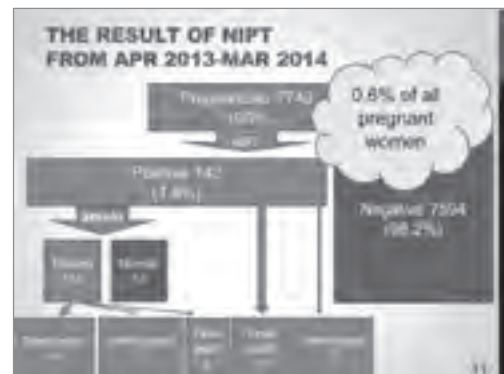
The point of these articles are that introducing NIPT will cause pregnant women to undergo the test easily, therefore the number of abortion after the test would be increasing. I was interviewed by several journalists from the newspaper company in Japan at my office. I asked them if you know how many abortions are conducted in Japan annually before you show the anxiety about abortions by results of prenatal testing. A young journalist said, "I don't know at all." The Japanese total number of abortion – annual abortion number - is about 200,000 a year. But now it's decreasing bit by bit, less than 200,000 abortions. I asked her, "do you know the number of abortions after prenatal testing in Japan?" She said, "I don't know." Then I said her, "you said that the abortion number would be increasing and become problems if we introduce NIPT." Actually, we don't know the precise number of the abortion after prenatal test. The only 3% of pregnant women maybe take it. Among them, maybe 1% or 2% of them would have positive results, then among them, about 90% will abort. It is very few case to have abortion after the result of prenatal testing.



When the NIPT was introduced, JSOG issued guidelines. They stated that the test should not be widely introduced into general obstetric prenatal practice. The test should only be carried out on pregnant women with an increased risk for fetal aneuploidy, and conducting the test in mass screening of pregnant women in general should be strictly prohibited.



Here in Japan, more than 7000 NIPT were undergone from April in 2013 to March, 2014. The result showed that 129 cases among 7,740 pregnancies are trisomy 13, 18 or 21. Most cases were negative through NIPT. It also showed that only 0.6% of all pregnant women were affected by taking the test and about 0.01% of all pregnant women had a positive result.



### Japanese History with regard to prenatal tests

And let me show Japanese history regarding prenatal tests. I wonder why Japanese people are cautious about prenatal tests. I think Japanese stand at the intersection of three historical lines. The three lines represent the population policy in relation to eugenics and the legal system of abortion, the feminist movement, and the disabled people movement. I don't have much time, so I just want to point out the important parts. The Meiji Government criminalized abortion under Japan's first modern penal code in 1880. The penal code was revised in 1907 to make abortion a more severe crime. But in 1940 during World War II, National Eugenic Protection Law was passed and it was modeled on the Nazi sterilization law.

|      |   |
|------|---|
| 1880 | Penal Code revised from 1880. It makes abortion a crime.  |
| 1902 | Birth Control Movement: Margaret Sanger was invited to Japan.   |
| 1921 | A legal precedent to allow doctors to perform emergency abortion to save a woman's life.  |
| 1931 | Feminist (first wave) organized Japan Birth Control League and Alliance for Reform of the Anti-Abortion Law. Dr. Oguro Kazuo published his theory for contraception (Oguro Method). |
| 1934 | Dr. Ohta Taro invented IUD (Ohta Ring) based on Gitterberg's Ring in Germany in 1930.   |
| 1935 | IUD and contraceptive methods except for condom were forbidden.   |
| 1937 | Birth Control Movement was forced to quit. Ishiro-Kato, Shintarō was arrested for Birth Control spreading action.   |
| 1940 | National Eugenic Protection Law based on the Law of Nazi Eugenic Sterilization.   |
| 1948 | Eugenic Protection Law legalized abortion under conditions. However penal code of abortion issued in 1907 continued to operate.   |

In 1948 after World War II, The Japanese government reformed the National Eugenic Protection Law, and renamed it to Eugenic Protection Act. It legalized abortion under several conditions such as

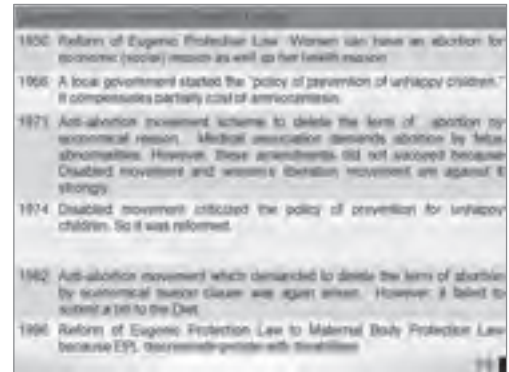


the health concerns of pregnant women, eugenic reasons including genetic disease of the pregnant woman and/or her spouse, and pregnancy due to sexual assault. However, The penal code of abortion was still valid.

In 1950, Eugenic Protection Act legalized abortion to decrease the birth rate. Then women could have abortions for economic reasons and social reasons. And in 1966 a local government started the policy of prevention of unhappy children. It reimbursed some part of the cost of amniocentesis. In 1973, the anti-abortion movement attempted to delete the term of abortion for economic reason. Medical association demanded abortion based on fetus abnormalities. However, these amendments didn't succeed because the disabled movement and the women's liberation movement are strongly against it.

In 1974, disabled movement criticized the policy of prevention of unhappy children. So it was reformed. In 1996, the Eugenic Protection Act was reformed to Maternal Body Protection Act because Eugenic Protection Act discriminated against disabled people.

In the brochure regarding the policy of unhappy children, it was described that children with disability cannot grow happily, therefore local government introduced the policy to "prevent the birth of unhappy children". The policy in 1970's included paying subsidies for amniocentesis to "prevent the birth of unhappy children". Activists of disabled people rights strongly opposed the policy.

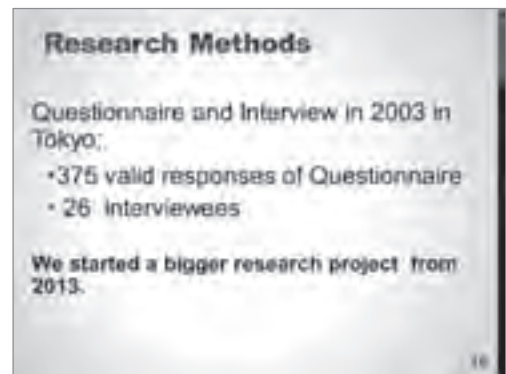


### Our research on Prenatal Test

In 2003, we conducted a questionnaire research with open ended questions and we had 375 valid responses to the questionnaire and interviewed 26 women. Now we have launched a bigger research project since 2013.

## Conclusion

I would like to conclude here. First, medical doctors emphasize that NIPS is non-invasive, so pregnant women might have a tendency to choose to have that test easily or without consideration. Second, Dr. Mills mentioned about the making decisions or the choice on prenatal test should be free. But many Japanese believe choice is not free. The women stand on intersection of the interrelationship of family and medical doctors. In such a kind of system, some women said that they tried to check the fetus because it was late childbearing and it might be hard for them to take care of a disabled child when they would get old. If they give birth to disabled children, women would feel guilty in the culture. Because Japanese women take the test to have to take responsibility for reproduction. JSOG issued the guidelines that doctors should not actively advise pregnant women on prenatal testing. If women would like to take the test, a medical doctor says, "Oh it's your choice." In other case, many women who didn't take a prenatal test said the reason why they didn't is as follows. Because her doctor didn't explain about prenatal testing directly but giving brief information by printing papers. When we ask in the questionnaire why you didn't take the test, many women responded, "oh, I'm healthy. I'm all right," "my doctor didn't mention about it. I think my doctor would inform me about the test if I had a problem. Many women know what prenatal testing is from the newspaper or the magazine, from the Internet. That's an authentic example of a typical Japanese attitude.



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### **Azumi Tsuge**

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Her recent publications are as follows:

Mimura K., Kokado M., Hong, H., Chang C., and Tsuge A, 2014. "Patient-Centered Development? Comparing Japanese and Other Gynecological Examination Tables and Practices", *East Asian Science, Technology and Society: An International Journal*, 8(3), pp.323–345

柘植あづみ、2012. 『生殖技術—不妊治療と再生医療は社会に何をもちたらすか』みすず書房

柘植あづみ・二階堂祐子、2014. 諸外国の出生前診断の状況とその背景 『日本医師会雑誌』 143(6),1166-1170 頁





Comment

## Prenatal Testing from a Legal Perspective

**Marcelo de Alcantara Ph.D.**  
Ochanomizu University



My area of expertise is law, particularly family law. So I am not sure if I will be able to contribute to the discussion on these ethical and social issues. But I would like to ask some questions as well as make some comments focusing on the legal issues related to prenatal testing.

### Choice and Consent

Today's seminar is entitled "Choice and Consent in Prenatal Testing", so the first question that comes to mind is "what is the difference between choice and consent", between "informed choice" and "informed consent"? Are the concepts or doctrines of informed choice based on those of informed consent? Is informed choice a pre-condition of informed consent? I think that the concept of informed choice is less familiar to most people in Japan.

On the other hand, informed consent has become a familiar word in everyday life, here in Japan and in other parts of the world, and means that a physician must inform a patient about the risks, benefits, and alternatives involved in any medical procedure and must obtain the patient's written consent to proceed. However, not all medical treatments require written informed consent. For example, in many countries ultrasound screening is used routinely and written consent is not considered necessary.

Ultrasound screening may detect fetus malformation, causing the woman emotional distress and leading her to face difficult decisions about the pregnancy. The same can be said for NIPT (non-invasive prenatal testing). If the NIPT result shows that the fetus has a chromosome condition, it can have significant emotional implications and affect women's reproductive autonomy. For this reason, a consensus emerged about the necessity of written informed consent that should be obtained from the patient before performing NIPT.

So, as Prof. Mills pointed out, there is not a coherent system of consent for non-invasive screening. Should same level of consent (e.g. written consent) be adopted for all non-invasive prenatal screening?

## **Routinization**

In the case of ultrasound, written consent is generally not required probably because it is performed as a routine procedure to screen for potential pregnancy problems, even where the woman is not at any particular risk.

And it is exactly this routinization one of the major concerns facing NIPT. It may become a standard test that most women undergo simply because other women undergo. Many people argue that NIPT should not be a part of routine pregnancy care because of the negative impacts on informed decision making. Routinization could, according to them, potentially undermine the decision-making process.

## **Wrongful birth claim**

Even though NIPT does not become part of routine pregnancy care, once the test is introduced to clinical practice, it might be expected that doctors offer this to the patients. Doctors must inform their patients about any known risks involved in a pregnancy, and failing to do so may lead to a medical malpractice lawsuit.

In a wrongful birth lawsuit, parents sue a doctor or hospital and seek damages for a child born with birth defects. The claim for damages is based on the cost to parents of raising an unexpectedly disabled child.

Parents in a wrongful birth lawsuit often claim that because they didn't have enough information to make an informed decision on whether or not to carry a pregnancy to term, their child was born with significant birth defects.

## **Restrictions on access**

However, on the other hand, there is also debate over whether NIPT should be limited to serious medical conditions. Some countries currently restrict NIPT to women at increased-risk, only offering NIPT to women of advanced maternal age or to pregnancies where there is evidence from ultrasonography of fetal anomalies.

## **Japan**

This is the case of Japan. As Prof. Tsuge mentioned, the Japan Society of Obstetrics and Gynecology has drawn up guidelines that limit the use of NIPT to a number of cases. So NIPT testing is available primarily to pregnant women of advanced maternal age and those found at risk of carrying babies with chromosomal abnormalities in earlier exams.

In addition, claims for wrongful birth are not generally accepted in Japan. The basic theory of a wrongful birth claim is that the doctor failed to advise the parents of the defect so that they could decide whether or not to terminate the pregnancy. But in Japan a doctor has no obligation to inform a patient about available testing that might reveal possible defects in a fetus.

### **Kyoto case (1997)** <sup>1)</sup>

In 1997, the Kyoto District Court decided a case involving a 39-year-old woman and her husband's complaint that their daughter was born with Down's syndrome because the doctor refused to conduct amniocentesis and, as a result, she was deprived of her right to decide whether or not to give birth to the child.

The woman became pregnant and was 39 when she gave birth in June 1994 to a girl with Down syndrome. The woman claimed she consulted her doctor, in February 1994, when she was 20 weeks pregnant, and told him she wanted to perform an amniocentesis as she was over age 35. However, the doctor refused to perform it, saying that the amniocentesis results would be available only after the time limit for a legal abortion in Japan, which is 22 weeks of gestation. The woman claimed damages for psychological, emotional and financial consequences of giving birth, including the costs of raising a child with Down syndrome.

The Japanese court ruled in favor of the doctor and accepted his argument that there was no violation of the woman's right to decide whether or not to give birth because even if the amniocentesis had confirmed Down syndrome, the pregnancy could not be legally terminated.

The court also concluded that it was a physician's discretionary authority whether he or she recommends a test and that there is no right to know in advance about genetic disorders in order to prepare for the arrival of a child with special needs. The court noted that receiving the diagnosis in this case could be an emotional and traumatic event and could be an incentive to seek out illegal abortion.

### **Case of R.R. v. Poland (2011)** <sup>2)</sup>

This approach, adopted in Japan, was recently challenged before the European Court of Human Rights.

In a case decided in 2011, the European Court of Human Rights held that Poland had violated the prohibition against inhumane and degrading treatment for denying a woman timely access to genetic testing. The woman had been denied access to an amniocentesis and an abortion, and she eventually gave birth to a child with Turner syndrome.

The case concerned a pregnant mother carrying a child thought to be suffering from a genetic abnormality. She was deliberately refused genetic tests during her pregnancy by doctors who were opposed to abortion, so she missed the time limit in Poland for a legal abortion and gave birth in July 2003 to a baby suffering from Turner syndrome. She brought suit against Poland arguing she was subject to inhuman and degrading treatment and that her rights to private and family life were violated.

The Court stated that the human rights resulting from article 3 (prohibition of inhuman or degrading treatment) and article 8 (right to respect for private and family life) of the European Convention on Human Rights were violated in denying her timely access to prenatal tests to determine whether the fetus was suffered from congenital abnormalities <sup>3)</sup>.

So, there are legal considerations surrounding the use of prenatal testing technologies, including national laws on abortion and assisted reproductive technology (ART). States will have to decide about regulating prenatal testing or not to ensure these technologies fit into existing legal frameworks of each country, and courts may face very difficult questions concerning reproductive autonomy and selective abortion.

## Endnotes

- 1) Kyoto District Court, Judgment, 24 January 1997. Hanrei Jiho, n. 1628, p.71.
- 2) European Court of Human Rights, R.R. v. Poland, no. 27617/04, Judgment of 26 May 2011.
- 3) The Polish government was ordered to pay the woman €60,000.

### **Marcelo de Alcantara**

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His research interests lie at the intersection of family law, comparative law and private international law, with a special focus on assisted reproductive technology issues and cross-border family disputes.

His recent publications and articles are as follows:

Marcelo de Alcantara, 2013. *National Reports: Japan*, in *International Surrogacy Arrangements: Legal Regulation at the International Level*, Katarina Trimmings and Paul Beaumont (eds), Hart Publishing, (in English)

Marcelo de Alcantara, 2013. *Brazil's Parental Responsibility Law*, *KOSEKI JIHŌ*, n. 695, 2013, pp. 11–17 (in Japanese)

Marcelo de Alcantara, 2011. *International Surrogacy: Legal Parentage Without Borders?*, *LEX MEDICINAE – REVISTA PORTUGUESA DE DIREITO DA SAÚDE*, 16, Coimbra, pp. 99–105 (in Portuguese)

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## Q&A

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### Q1. About apparatus of choice

**Speaker 1:**

I have a question on the Apparatus of Choice. I think this is based on Foucault. Right?

**Catherine:**

Yes.

**Speaker 1:**

Yes, okay. Based on the interpretation of Foucault, in my understanding – maybe I am wrong, because I need to digest your explanation – you've mentioned there is a sort of uncertainty generated by technologies. So, there can be issues – something difficult for people to understand well. Think about brain death, for instance. Usually people couldn't understand what's going on when they face the situation, but a doctor gives some information and a patient's family will just accept that because the issue is so difficult to follow and because often they are under so much pressure.

**Catherine:**

Yes.

**Speaker 1:**

Their decisions should be free from that. So my point is... Do you agree if I say we are often not like that, or make judgments, just as described in your explanation?

**Catherine:**

Yes. Look, I think that's true. I think the question is how we kind of think about the status of these elements - whether they are normative principles which ought to be met, whether they're kind of criteria that ought to be met, or whether they are, when we look at the kind of things people are saying and doing, they're the kinds of things that people talk about regardless of whether practice actually meets these criteria or norms. So I'm interested in the second approach, I guess, which is to say, okay, these are the things people talk about – I mean knowledge, for instance, or being sufficiently informed. There's a lot of talks about being sufficiently informed across various medical contexts, I guess. But whether someone is sufficiently informed or not or what even counts as being sufficiently informed is really not often clear, but the discourse of what people say is still about being sufficiently informed. So what I'm trying to get at is not whether there's a – not whether they're kind of satisfying as criteria but whether they are present as discursive elements, I guess.

**Speaker 1:**

Yes. I got it. Thank you.

**Catherine:**

Yes, yes. And I think just secondly, it probably varies in relation to different contexts as well.

**Speaker 1:**

Exactly.

**Catherine:**

So I'd be very interested to hear more about – or to see more about how this operates in relation to brain death.

**Speaker 1:**

Actually, the thing is how doctors are involved in making decisions in brain death cases....

**Catherine:**

Yes, yes. That's right. Yes. So in that context you might see that clinicians are actually much more involved or someone's much more involved in leading people through that decision making process because it's just so shocking and difficult, yes—though I've also heard people say or some colleagues of mine comment on how it's often..., especially with younger clinicians, it's all just about, well, your choice, which the older doctors find difficult because for them the practice would be to be more involved. So, there's a generational difference as well, I think.

## **Q2. Ultrasound test in Australia**

**Speaker2:**

In Australia, how many times do pregnant women take ultrasound during their pregnancy?

**Catherine Mills:**

Twice. Sometimes if a woman has a private obstetrician they might do a test in their office or they might look at the baby every time, she goes. But that's not a test. There are some obstetricians in Australia trained on ultrasound. But most obstetricians aren't, so one of the complaints is that when women have their ultrasound scan in their obstetrician's office, that's not telling them whether there's anything wrong. In fact the obstetrician may not have any training in using an ultrasound. So it reassures women but it's a false sense of reassurance. The untrained obstetricians couldn't tell them whether there's anything wrong. Ultrasound is assumed to be diagnostic, so the obstetricians trained on ultrasound worry about its use by untrained doctors. And so there's a debate in the college about how to handle obstetricians not trained in ultrasound.

## **Q3. How many Australian women undergo ultrasound?**

**speaker3:**

What percentage of Australian women undergo ultrasound?

**Catherine Mills:**

My sense is that almost all women will have the 18-week scan, almost all pregnant women who are planning to carry to term will have the 18-week scan. And most women will have a 12-week scan as well. It's recommended to all women that they have the 12-week scan at the obstetrician, but it's especially strongly recommended for women over 35. Some women decide not to because even if their baby has Down syndrome they will carry to term. But what's interesting is that the first scan has come to be seen as a test about Down syndrome, even though they test for other things early.

**Speaker3:**

You mean that the first ultrasound scan is to find Nuchal Translucency?

**Catherine Mills:**

Yes. That's right.

**Speaker3:**

And combined with the maternal serum?

**Catherine Mills:**

Yes. Combined with blood test and maternal age.

#### **Q4. About not taking a prenatal test**

**Speaker4:**

Maybe I missed some points. Do you think that the main issue of pregnant women in Australia is not taking the prenatal test?

**Catherine Mills:**

Yes. I should say that. But to my mind, this is a problem because – I mean this is partly contextual, Melbourne is a very multicultural city. There are lots of recent immigrant women who just don't speak very good English, and they don't read English. They have no way of being informed because no one is providing them with the information in a way that they could understand.

So to my mind, it's not that they are irresponsible but they come to be seen as irresponsible within this process of making them make choices. I think there is a lot of emphasis on them making choices and who's making – I want to say the right choice — because on the one hand women are afraid to make whatever choice they like. But in fact some choices get more supported than others, I think. I think the legal questions are difficult. Professor Marcelo, you made the point that these technologies need to fit within the legal frameworks, the existing legal frameworks and I think that is so correct. What we see is an enormous amount of tension between the technologies and the law, as these cases reveal.

And one worry or one of the things that is probably going to happen in Victoria, where I live,



is that we will see more terminations on the basis of fetal sex, because we have abortion on demand, you can have an abortion up to 24 weeks without having to give any reason. There's not even an indication of why you're having a termination. And with NIPT, you can find out the fetal sex at 12 weeks. So you've got a long window then to decide. And a lot of doctors and a lot of other people are worried that this will lead to more sex selective termination because Victoria has quite liberal abortion laws now and that's one of the concern with NIPT.

**Speaker5:**

After the 24 weeks, perhaps a client cannot abort the fetus.

**Catherine Mills:**

Well, after 24 weeks I mean you would've had an 18-week scan in any case by that stage. So at 18 weeks, you could find out the fetal sex at that point. So even they need to – if you wanted to make sure you had a girl or a boy, you could still terminate following that. It's difficult, I mean it's a sort of risk factor at 18 when then you would have to make a decision about whether you'd have NIPT or amniocentesis. Yes. But mostly you would be thinking about amniocentesis because you should've – if it was Down syndrome or something that you could be tested for with NIPT that would have shown up at 12 weeks. But it's complicated. I mean this is why – this is a complicated question and no one really knows how NIPT fits in because of these various questions. So as you mentioned, it's being recommended as a test for women in high-risk categories like advanced maternal age, where they get a much clearer indication that leads to the – obviously, the Down syndrome and a much smaller false positive. That is the main benefit.

You'd look – it's interesting it's difficult to actually know what's happening here because on the one hand Australia doesn't collect very accurate statistics about abortion because it's based by state and because when it's coded as a gynecological procedure under Medicare, but there can be a whole range of procedures. So it's really hard to know how many women are actually having terminations. The sense is that more women have terminations on the basis of Down syndrome diagnosis than may have been the case, but at the same time one person involved in disability advocacy told me that the rate of live births for Down syndrome hasn't changed. So that's because younger women are having children with Down syndrome because they're not having the nuchal translucency test because it's not necessary – it's not strongly recommended to them.

**Q5. Disable child isn't unhappy?**

**Speaker2:**

I've lived in United. I often saw many Down Syndrome people in places like super markets and public places. I think that more than a little prenatal women don't choose termination if they would find that a fetus has a risk of Down syndrome.

**Catherine Mills:**

Yes.

**Speaker3:**

In the United States, Down syndrome is still unwilling so much because it's a recognized as disability or malformation. When I talked with women in the United States, they said to me that we met many Down syndrome people in Tokyo. So the – I am not sure about it. I cannot agree with it.

**Catherine Mills:**

Nancy Chris actually has a very interesting article where she and another colleague did a study of attitudes towards disability. And the point that she makes is that while people might have generally positive attitudes towards something like Down syndrome in particular, they still don't want their child to have it. So even though they might have kind of warm and fuzzy feelings about Down syndrome and think that it's fine, they don't want their child to have Down syndrome. Though interestingly one state, I think it's Ohio in the USA, it's now trying to ban abortions on the basis of Down syndrome. Why?

**Speaker2:**

Ohio?

**Catherine Mills:**

Ohio I think, yes.

**Catherine Mills:**

Though it's quite expensive raising a child with a Down – with a disability or it can be quite expensive and there's not very much social support in the US. Any differences between the desire for the normal child and the unhappy child. That's interesting, I mean, let's say it's an interesting idea that a disabled child is an unhappy child to begin with. I think that, to me, one of the points that's interesting is the idea that because prenatal testing can tell you whether your child will be normal in some sense, a genetic sense or chromosomal sense, it is also telling you that your child will be happy and will have a good life, which of course it isn't. Okay? Because, for one thing – and prenatal testing can't do this. It can't tell you whether your child is going to have autism for instance, which many people will say it's much worse, would be much harder to raise a child with autism than raise a child with Down syndrome. It can't tell you that your child will fall over in a playground and acquire a disability that way. It just can't tell you all of these things about the well-being of your child. But I think it has become understood to actually – to make this connection between normal and happy, and I think that's what happens when people think about prenatal testing is that they think in those terms. Genetically normal means good life and it just doesn't yeah, that's what I think, yes.

## IGS Seminar Report on IGS website

### Choice and Consent in Prenatal Testing

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The IGS Seminar “Choice and Consent in Prenatal Testing” was held on November 18, 2015 at Ochanomizu University. The main theme of the seminar was “Are decisions about prenatal testing by pregnant women truly their choice?” Pregnant women face decisions such as whether to undergo prenatal testing or whether to abort a fetus when tests results suggest disability. Dr. Catherine Mills (Monash University) and Dr. Azumi Tsuge (Meiji Gakuin University) gave presentations on issues related to prenatal testing based on their respective research in Australia and Japan. Responding to their presentations, Dr. Marcelo de Alcantara (Ochanomizu University) gave comments from his perspective as a legal researcher.

From the viewpoint of bioethics and feminism, Mills referred to the self-determination of pregnant women with regard to prenatal testing. Mills provided examples of ultrasonography practice in Australia and then explained the concepts of “normalizing” and “apparatus of choice.” Because people are greatly affected by their culture and social environment when making choices, prenatal testing may be associated with discrimination and bias against disability. Pregnant women often undergo ultrasonography without recognizing it as prenatal testing because it isn’t invasive. Since it was introduced, Non-invasive Prenatal Testing (NIPT) has been widely adopted in Australia because it requires only a blood sample from the pregnant woman and therefore places no burden on her or her fetus. Informed consent and counseling are required before NIPT, but such procedures are not required in the case of ultrasonography. Citing a book written by Foucault, Mills referred to the nature of biopolitics and disciplinary power since the 18th century. The basic concept of biopower is the socialization of reproductive power and reproductive activity in association with the pathologization of certain conditions for the maintenance and promotion of health and well-being of individuals and the society as a whole. Mills suggests that ultrasonography is a medical technology that promotes standardization and is an apparatus of choice that make pregnant women to choose to abort when a possible disability is detected. In other words, prenatal testing should work to enhance pregnant women’s autonomy based on their moral or ethical principles. However, in practice, testing without informed consent and counseling may lead to the elimination of disabled children because women’s decisions may be influenced by the widespread negative image of disability.

After Mills’ presentation, Tsuge introduced the current situation in Japan. Apart from ultrasonography, the number of practiced prenatal tests (such as amniocentesis) in Japan is significantly smaller than in other developed countries. According to Sato, a leading researcher of prenatal testing in Japan, the number of maternal serum marker tests performed in the U.S. is 167 times larger than in Japan and the number of amniocentesis tests performed in Germany is 10 times larger. A survey in 1999 reported that only 3% of all pregnant women received prenatal testing based on maternal serum markers in Japan. The Health and Welfare Ministry and gynecologists made a statement in 1999 that pregnant

women did not necessarily need to be informed about maternal serum marker screening; their reasoning was that the test might result in an increase in abortions of fetuses with disabilities. NIPT was introduced in 2013 in Japan, but it is only available for pregnant women of age of 35 or older. Before NIPT was introduced, there was a controversy about whether it would result in increased “casual” abortions based on eugenic thinking, particularly for pregnant women in higher age groups. Of nearly 200,000 cases of abortion performed annually in Japan, probably only 1% to 2% can be ascribed to the results of prenatal testing. Only 0.6% of the 7700 NIPTs conducted since the test’s introduction in 2013 have given positive results. Based on these data, Tsuge raised doubts about the idea that testing would increase abortion. She also explained the history of prenatal testing in Japan. Although abortion has been prohibited by the Criminal Law, prenatal testing has been promoted in connection with eugenics and in association with the Eugenic Protection Act and the Maternal Protection Act.

Following the reports by the two speakers, Alcantara gave comments from a legal perspective. Referring to two past cases in involving prenatal testing, he pointed out the possibility that physicians might suggest prenatal testing in order to preclude Wrongful Life lawsuits (filings for unwanted babies) in the future. The first case was brought in 1997 by a woman aged 39 and her husband in Kyoto who gave birth to a baby with Down syndrome. Even though the woman told the doctor of her desire to receive an amniotic fluid check in the 20th week of pregnancy due to anxiety about her age, the doctor refused to provide the test, saying that it was meaningless because the result would be obtained only in the 22nd week of pregnancy, when the option of abortion was no longer available. The doctor’s claims were accepted by the court, and the couple lost the case. In another lawsuit case heard by the European Court of Human Rights in 2011, a Polish woman who gave birth to a baby with Turner’s syndrome insisted that her individual and family rights to subsistence were impaired by giving birth to a disabled baby, which resulted from her doctor’s negligence in providing her with information regarding prenatal testing during the period when abortion was available. This case was initially taken initially to court in Poland and later went to the European Court of Human Rights, which upheld the woman’s claims, resulting in her victory. As these cases reveal, choices and decisions by women have been controlled socially by being linked with ideologies such as eugenics, even if childbirth and raising are personal matters.

IGS Project Research Fellow  
Yukari Semba, Ph.D

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## Seminar Report on IGS website

### 第3回 IGS セミナー：キャサリン・ミルズ先生を迎えて

#### Choice and Consent in Prenatal Testing（出生前検査における選択と同意）

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2015年11月18日(水)にお茶の水女子大学にて、ジェンダー研究所主催のIGSセミナー「Choice and Consent in Prenatal Testing(出生前検査における選択と同意)」が開催された。本セミナーはすべて英語で行われ、その主要なテーマは、妊娠している女性が出生前検査を受検するか否かの選択や、検査で胎児に障がいのある可能性が提示された場合、女性たちの産む・産まない選択は本当に自立的決定であるかという問題であった。セミナーではモナシュ大学のキャサリン・ミルズ氏と明治学院大学の柘植あづみ氏が、それぞれオーストラリアと日本の出生前検査の現状を踏まえ、検査に関する問題を提起し、その後、お茶の水女子大学のマルセロ・デアウカンタラ氏が2人の報告を踏まえて法学研究者の立場からコメントした。参加者は9名であったが、深いディスカッションができた。

第一スピーカーのキャサリン・ミルズ氏は、バイオエシックスやフェミニズムの視点から妊婦の出生前検査に関する女性たちの自己決定に言及した。オーストラリアの特に超音波検査実施の現状を例にあげ、標準化(Normalizing)、選択装置(Apparatus of Choice)をキーワードに話をすすめた。人が何かを選択するとき、文化や社会環境に大きく影響を受けるが、出生前検査に関しては、障がいに対する差別や偏見と結びついている。超音波検査は妊婦や胎児にとって非侵襲的であるため、これが出生前検査であることを自覚しないまま妊婦たちが受検している点も問題として提示した。最近、オーストラリアでもNIPT(Non-invasive Prenatal Testing—新型出生前検査)が導入され、これも妊婦の血液の採取だけで検査が可能で非侵襲的なために、検査が普及しつつある。しかし少なくとも、NIPTでは実施前にインフォームドコンセントやカウンセリングがあるが、超音波検査にはこれらがない。ミルズ氏はフォーコーの著作をあげ、18世紀以降のバイオポリティクスの本質や、とくに規律権力(disciplinary power)に言及した。生権力の基本的な考え方は、個人や全体の健康やウェルビーイングを維持・促進することに関心をむけた生殖の権力(reproductive power)や生殖行動の社会化であり、ある状態を病理化することと関連する。ミルズ氏は超音波検査が標準化のための医療技術であり、妊婦に一定の選択をさせる装(apparatus of choice)となっている。つまり道徳的原則や倫理原則を掲げて、妊婦の自律を尊重して検査も中絶も妊婦の選択だという姿勢を示しているが、妊婦は現実には、障がいに対するイメージから、障がいの可能性があれば中絶を選択することが多く、超音波検査が障がい児排除の方向へとむかわせているというのだ。



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[http://www.igs.ocha.ac.jp/igs/IGS\\_Tushin/#d11](http://www.igs.ocha.ac.jp/igs/IGS_Tushin/#d11) 参照

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この議論を受けて、次に明治学院大学の柘植あづみ氏が日本の状況について説明した。日本では超音波検査以外の出生前検査（羊水穿刺等）の実施件数は他の先進国に比較すると非常に低い。日本の出生前検査の第一人者、佐藤のデータによればアメリカでは母体血清マーカー検査は日本の167倍、ドイツでも羊水穿刺が日本の10倍も実施されている。1999年の調査では、日本の妊婦全体の3パーセントしか母体血清マーカーによる出生前検査を受けていないと報告されたが、旧厚生省と産婦人科医は1999年、妊婦に積極的に母体血清マーカーという出生前検査のことを知らせなくてもいいという声明をだした。これは国や産科医たちが障がいのある胎児の中絶が増加することを懸念したからである。日本ではNIPTが2013年から導入されたが、35歳以上の妊婦しかこれを利用できない。導入前には、妊産婦の年齢が高くなっている日本で、この検査は優生思想による安易な中絶に結びつくとその賛否が議論された。日本では現在年間約20万件弱の中絶が実施されているが、出生前検査の結果の中絶はわずかにすぎない。おそらく全体の1～2%ほどだと推測される。2013年にNIPTが導入されてから、検査の実施件数は7700件であり、そのうちの0.6%しかNIPTで陽性反応がでていない。にもかかわらず、この検査で中絶があたかも増えるという考え方がでてくることに対し、柘植は疑問を呈した。その後、柘植氏は日本の出生前検査が優生思想と深く結びつき、墮胎の罪で中絶が刑法で禁止されているのに、優生保護法や母体保護法と関連を持って、すすめられてきた経緯を紹介した。

これら二人の報告を受けて、マルセロ・デ・アウカンタラ氏が法の専門家としてコメントをした。アウカンタラ氏は出生前検査に関連する過去にあった2つの事例をあげて、いずれ医師がWrongful Life訴訟（生まれたいほうがよかったと提訴）を避けるために、出生前検査を提示するようになる可能性があるという。最初の事例は1997年に京都で39歳でダウン症の子どもを出生した女性とその夫が起こした裁判である。女性は年齢的な不安から妊娠20週目に医師に羊水検査を希望する旨を伝えたが、医師は中絶ができなくなる妊娠22週目以降にしか結果がでないため、羊水検査は無意味だと検査の提供を拒否した。裁判では、この医師の主張が認められ、女性と夫は敗訴した。もう一例は2011年に欧州人権裁判所でおこった裁判で、ターナー症候群の子どもを出産したポーランド人の女性が、医師が中絶可能な期間に検査について情報提供を怠ったために、障がいのある子どもを産んで個人と家族の生活権が侵されたと訴えた。女性はポーランドの裁判所にも訴え、最終的に欧州人権裁判所に持ち込まれ、この裁判では女性が勝訴したという事例をあげた。出産・育児は個人的なことだが、それが優生思想等と結びつき、女性の選択や決定が操作されている点が明らかになった。

（記録担当：仙波由加里 IGS 特任リサーチフェロー）



## Power Point Slide: Catherine Mills

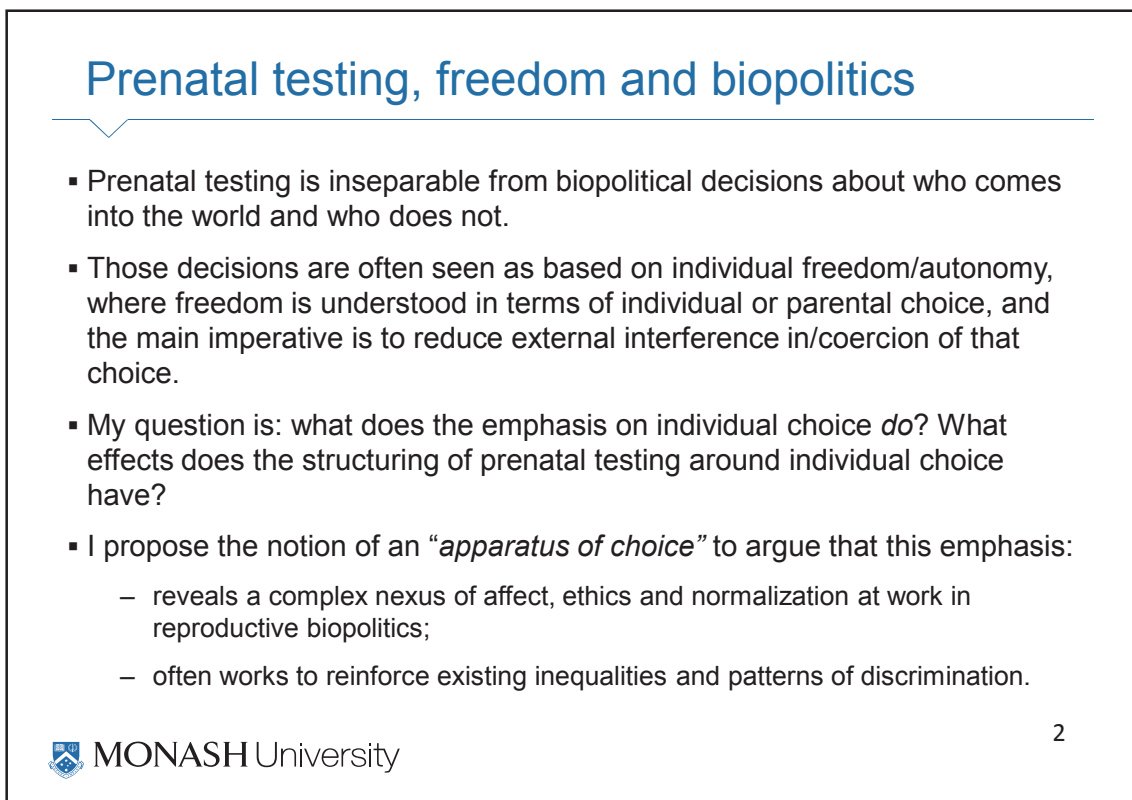


Choice and consent in prenatal testing in  
Australia

26 November 2015


Assoc. Prof. Catherine Mills  
ARC Future Fellow  
Centre for Human Bioethics

 MONASH University 1  
monash.edu



Prenatal testing, freedom and biopolitics

- Prenatal testing is inseparable from biopolitical decisions about who comes into the world and who does not.
- Those decisions are often seen as based on individual freedom/autonomy, where freedom is understood in terms of individual or parental choice, and the main imperative is to reduce external interference in/coercion of that choice.
- My question is: what does the emphasis on individual choice *do*? What effects does the structuring of prenatal testing around individual choice have?
- I propose the notion of an “*apparatus of choice*” to argue that this emphasis:
  - reveals a complex nexus of affect, ethics and normalization at work in reproductive biopolitics;
  - often works to reinforce existing inequalities and patterns of discrimination.

 MONASH University 2



## Prenatal testing in Australia

- Screening tests available: ultrasound, (in conjunction with maternal blood test for trisomy conditions); recently, cell-free fetal DNA testing (often called NIPT, NIPS); microarray testing; diagnostic tests such as amniocentesis and CVS.
- Well-established regime for ultrasound screening: 12wk and 18wk scans, available in both public hospitals (for some patients) and private ultrasound or radiography clinics.
- Public subsidies through Medicare for ultrasound tests, for all 18wk scans and many but not all 12wk scans. Not for other screening tests.
- National guidelines for ultrasound testing are provided by Australian Society of Ultrasound Medicine (ASUM), and Royal College of Obstetricians and Gynecologists
- These are guidelines only
- What clinics test for, what markers they use, can vary (eg. Nasal bone in DS testing)
- Ongoing accreditation requirements to ensure quality of service
- ASUM has issued document on normal range fetal measurements that is widely used.

## Choice and consent

- How does the introduction of cell-free DNA testing (known as NIPT) relate to and affect ultrasound testing?
- Changing rationale for/practice of 1<sup>st</sup> trimester scan
- Also reveals contradictions in approach to choice and consent in non-invasive prenatal testing regimes.
- Ultrasound requires informed choice; NIPT requires informed consent.
- Would an explicit consent procedure for ultrasound diminish some of the effects of the apparatus of choice, or is it just a different manifestation of the same phenomenon?

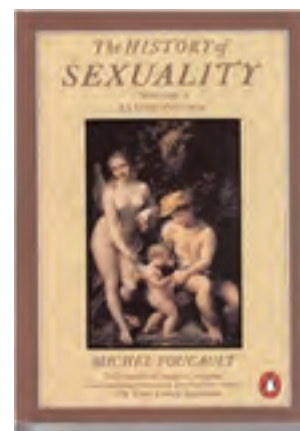


## The study

- ARC DP with Niamh Stephenson(UNSW) and
  - Research assistance: Kim MacLeod (UTas) and Helen Ngo (Monash)
- Qualitative study of obstetric ultrasound (OU) in Australia
- Interviewees recruited from both private clinics and public hospital settings
- Semi-structured interviews as well as (9) observations of ultrasound scans
  - 26 women interviewed, following either 12 week nuchal translucency scan or 20 week fetal morphology scan
  - 27 professionals, including sonographers, obstetricians, genetic counsellors, disability advocates
- How ultrasound impacts on ideas of moral status of fetus, and decisions about selective termination (ST)
- Didn't set out to focus on choice, but quickly became evident that this was a major trope in almost all reflections on the experience of undergoing or using OU

## Biopolitics and reproduction

- First, establish the *biopolitical* nature of the context of prenatal testing:
- Foucault on biopower: “the ancient right to *take* life or *let* live was replaced by a power to *foster* life or *disallow* it to the point of death” (HS 1, 136) .
  - 2 poles - discipline and biopolitics
  - tied together in deployment of sexuality
- “Sex was a means of access both to the life of the body and the life of the species” (1990, 146)
- “Socialization of procreative behavior” was one of the “four great strategic unities” that formed the mechanisms of a power focused on sex (103-4)
  - Political socialization through responsabilization
  - Medical socialization through pathologization



## Transforming reproduction

- Technologization
- Commercialization
- Normalization
  - Ultrasound as pre-eminent normalizing technology
    - necessarily operates within a context of the medical management of risk and uncertainty on the one hand, and the political management of population wellbeing on the other
    - However, norms that underpin ultrasound practice do not in themselves require the eradication of the abnormal. Rather, the eradication of the abnormal points to their location and operation within moral and affective economies of the normal
- The “desire for the normal” (Kittay) is channelled through choice, revealing nexus of affect, ethics and normalisation

## PNT and Choice

- This is consistent with bioethical/biomedical emphasis on the standard of *informed choice* as required to undertake prenatal screening
- Yet clinicians (obstetricians, sonographers, genetic counsellors) expressed the concern that women were *insufficiently informed* about having the ultrasound test, its purpose etc
- Worried that women did not appreciate that ultrasound screening is a medical examination; that it has potential consequences; that it may require them to make difficult decisions
- At the same time, they also strongly valued *non-directiveness* when an anomaly is found, so that the decision to terminate is understood as an expression of woman’s autonomy
- In particular, there was a strong emphasis that it was a woman’s decision whether or not to terminate a pregnancy following indications of fetal anomaly (though with the caveat that not all requests for termination are necessarily supported)

## The apparatus of choice

- How might this emphasis on choice be understood and its effects analysed?
- There is a strong concern in feminist bioethical literature that choices made are not genuine choices – (eg, because women are insufficiently informed), or that it is mere fantasy that genuine choices can be made in this context (Kittay, Paul)
- This is not my approach; rather, I ask, what does the emphasis on choice do? Can we understand the effects of the operation of choice?
- Propose the notion of an ‘apparatus of choice’?
- What is an ‘apparatus’?
  - Relatively cohesive and coherent conglomerate of material and discursive elements that shape but do not determine behaviour in a given context
  - Operates differently in different contexts, but some consistent characteristics

## Elements of the apparatus of choice

- Foucault highlights the three axes of subjectivity, knowledge and normativity as ways of tracing an ‘apparatus’ and its effects
- In the apparatus of choice:
  - **Subjectivity:** presupposes subject capable not only of making choices, but of making *rationaly justifiable* choices
  - **Knowledge:** emphasis on being ‘informed’, where this primarily means in terms of medical view of an anomaly; but also state of knowledge re anomalies etc; uncertainty generated by technology itself
  - **Normativity:** choices are understood as needing to be ‘free’, ie, unimpeded by others. Liberal notions of negative freedom, autonomy as independence etc. Strongly individualistic focus.

## Clinicians as service providers

- Allows clinicians to adopt position of moral neutrality, and also forces them to, even if they would like to provide more engaged care.
- Emphasis on non-directive information provision, both prior to and after PNT.
- However, prior to ultrasound, the standard of informed choice and implied consent rather than express consent means that no-one takes responsibility for providing information or ensuring that women are sufficiently informed.

“This is simply about providing information that allows women to make their own choices” – Ben, Obstetrician

“People have individual choice and might not make the same decisions as me. And I think, if they can rationalise that and, you know, it, they put together a sensible argument, then I’m here to, to help them through the difficult time. But, yeah, I mean there would be circumstances where I know the hospital would say, “No, that’s not reasonable.”” - Ben, Obstetrician

## Clinicians as service providers

- After testing, (non-directive and neutral) roles as clinical agents can be more or less strictly held, but either way, moral responsibility for any decision is projected onto women.
- Clinicians are reluctant or unable to publicly reflect on the moral ambiguity of their roles (even if they want to).
- The apparatus of choice allows clinicians to avoid the moral ambiguity of their practices and project responsibility solely onto women.
- Some clinicians are very reflective about this.

“Have we become more sophisticated in our counselling? No doubt. Are women more aware of their choices? Yeah, almost certainly. You know, are most better, women better off? I’m not sure.” Ken – Sonographer

“So I don’t think we do give women lots of choice. I think we give them lots of information and we sometimes bamboozle them, and then we say, “It’s all your choice.” And, in a way, we’re kind of handing over professional responsibility.” – Deanna, genetic counsellor

## Women as moral actors

■ 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

OR

■ Fundamentally ir-responsible, incapable of informed decision-making but nevertheless culpable for this (perceived) moral failure

- For example, women who are insufficiently informed about or respectful of the medical aspects of ultrasound (as opposed to the social) are seen as irresponsible and morally culpable for this failure.
- Women who do not read English, or who do not have easy internet access, also fall into this category.



“I always get the sense that I’m kind of on my own to make the final, the final choice” – Maria, 12 wks pregnant, considering amniocentesis

## Women as moral agents: further aspects

- Control of information: lack of consent process means women are made responsible for their own condition of being informed or uninformed
- Control of her body: ideal woman having ultrasound is thin, but not too thin; her bladder is full, but not too full; her baby is active, but not too active
- Control of emotions: ideal woman having ultrasound is concerned but not anxious, engaged but not demanding

“The super-anxious ones are difficult...” Beatriz, Sonographer

“.. when woman comes in here with her girlfriend, that’s a nightmare. They talk about all their shopping expeditions and their friends, and their social ... And I think, “What are you doing here?” Beatriz, Sonographer

## Fetus as boundary object

- The apparatus of choice makes the fetus something about which one makes choices
- These choices are ones about the differential valuation of life and possible lives
- It also makes the normative status of fetus – its inclusion in moral community and normative life – dependent on technology
- Intersects with medical normalization
  - Disability and norms
- Not only choices made, but choices made available (Nancy Press)
  - social structures within which choices can be made at all
  - The apparatus of choice tends to obscure this aspect of the material conditions of choice

## Ultrasound and Cell-Free DNA test (NIPT)

- Available at various clinics in Australia since about 200?
- Samples generally sent overseas, but Victorian Clinical Genetic Services recently developed Australian test, called percept
  - <http://www.vcgs.org.au/perceptNIPT/>
- High rate of accuracy, but not diagnostic; amnio or CVS still required for diagnosis
- 12wk ultrasound still recommended (in conjunction with cfDNA test)
- Costs around \$500; this is **not** subsidized by the govt, nor is there currently any discussion of incorporating cfDNA tests into the publicly subsidized prenatal screening regime.
- As it only requires a blood test, there is no risk to the pregnancy.
- Other tests: Harmony, Panorama (microdeletions; tests for Angelman, Cri du Chat, DiGeorge, Prader-Willi Syndromes)

What will this test tell me?

| Conditions screened                 | Detection Rate |
|-------------------------------------|----------------|
| <b>Trisomies</b>                    |                |
| Down syndrome (Trisomy 21)          | >99%           |
| Edwards syndrome (Trisomy 18)       | >99%           |
| Tau syndrome (Trisomy 13)           | >99%           |
| <b>Sex chromosome conditions</b>    |                |
| Y chromosome microdeletions (X)     | >99%           |
| <b>Chromosomal conditions (LOP)</b> |                |
| 1q21.31 (DGS)                       | LOP            |
| X11 syndrome                        | LOP            |

| Gender               | Accuracy |
|----------------------|----------|
| Male (Y), female (X) | >99%     |

Accuracy in isolation

[http://www.vcgs.org.au/downloads/perceptNIPT/CT-W-138v3\\_web.pdf](http://www.vcgs.org.au/downloads/perceptNIPT/CT-W-138v3_web.pdf), p1.

## Choice and consent in non-invasive screening

- cfDNA tests such as percept require explicit patient consent; the standards of informed consent are (supposed to be) applied
- Ultrasound is also a form of non-invasive screening
- It does not require a consent form to be signed; the standards of informed choice are taken to be sufficient.
- There is no principled justification for this difference; the contradiction is an historical artefact of the ad hoc introduction of ultrasound (and now cfDNA testing)
- Would a coherent system undo the requirement for consent in cfDNA, or introduce it for ultrasound?
- While there are problems with consent procedures, the introduction of consent for ultrasound may ameliorate some of the negative effects of the apparatus of choice in regards to ultrasound – eg, making women responsible for being informed, addressing clinical concern with lack of knowledge, and associated lack of preparation for high risk results

## Conclusions

- The apparatus of choice casts women as the principian – indeed, only – moral agent who bears responsibility for PNT decisions.
- The clinical introduction of cell-free DNA testing in Australia, puts pressure on the emphasis on informed choice for non-invasive screening, since it requires explicit consent.
- Though consent is only a formalization of choice, a shift toward a coherent consent system across non-invasive screening techniques may alleviate some of the negative effects of the apparatus of choice.
- More research is required on whether a consent system would be feasible or desirable.





## Power Point Slide: Azumi Tsuge

WHAT DO WOMEN WANT  
TO CHOOSE IN PRENATAL  
TESTING IN JAPAN?

AZUMI TSUGE, PH.D  
PROFESSOR AT MEIJI  
GAKUIN UNIVERSITY

1

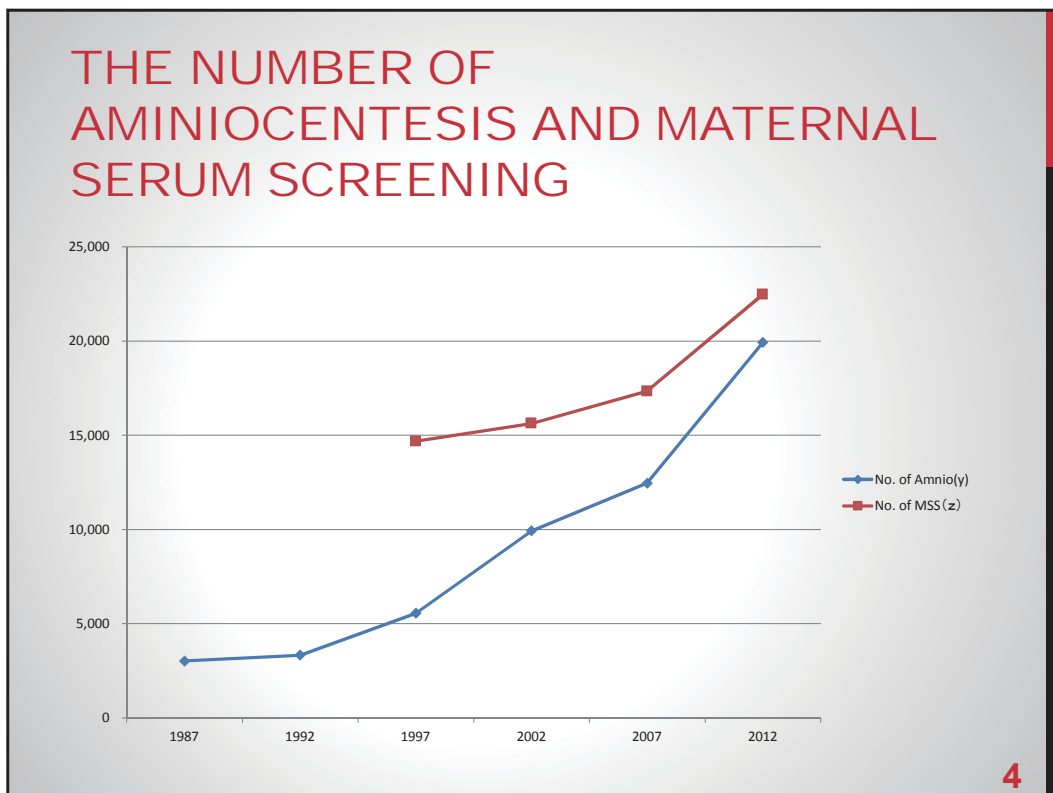
PRENATAL TESTS IN JAPAN

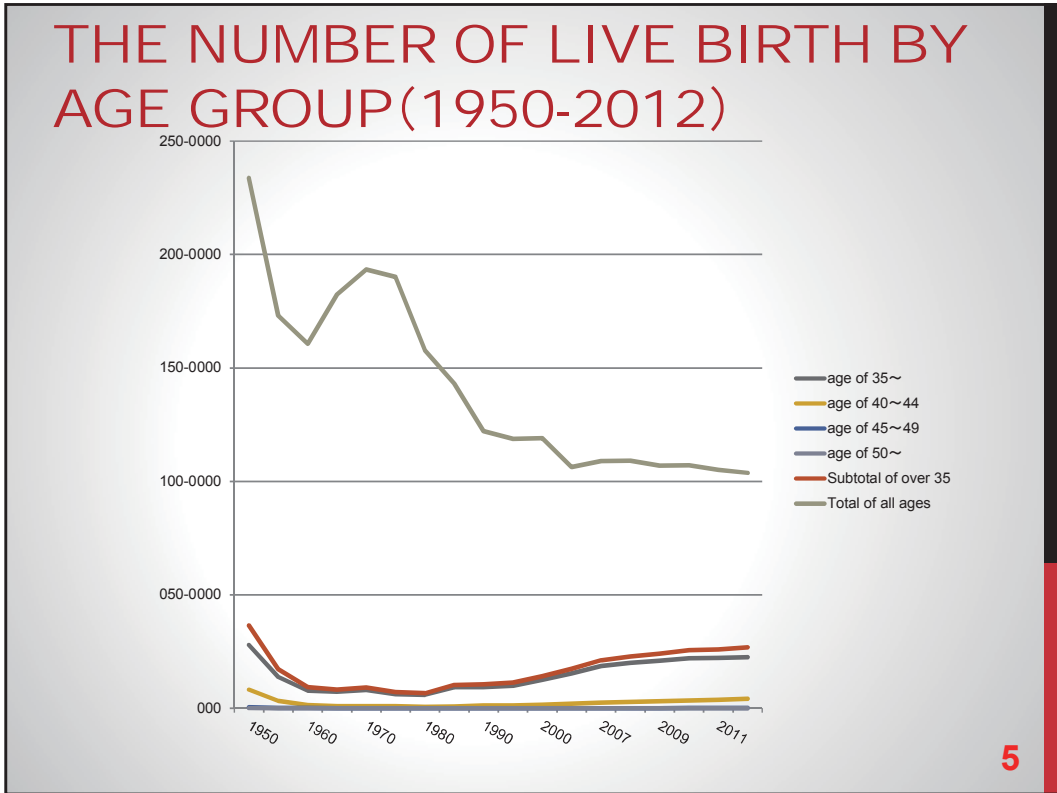
- **The ratio of women undergoing prenatal genetic tests is low in Japan**
- **Only 3% of all pregnant women received prenatal diagnosis other than ultrasound scanning**
- **Abortion is allowed, but it is not allowed by the reason of fetal abnormality**

2

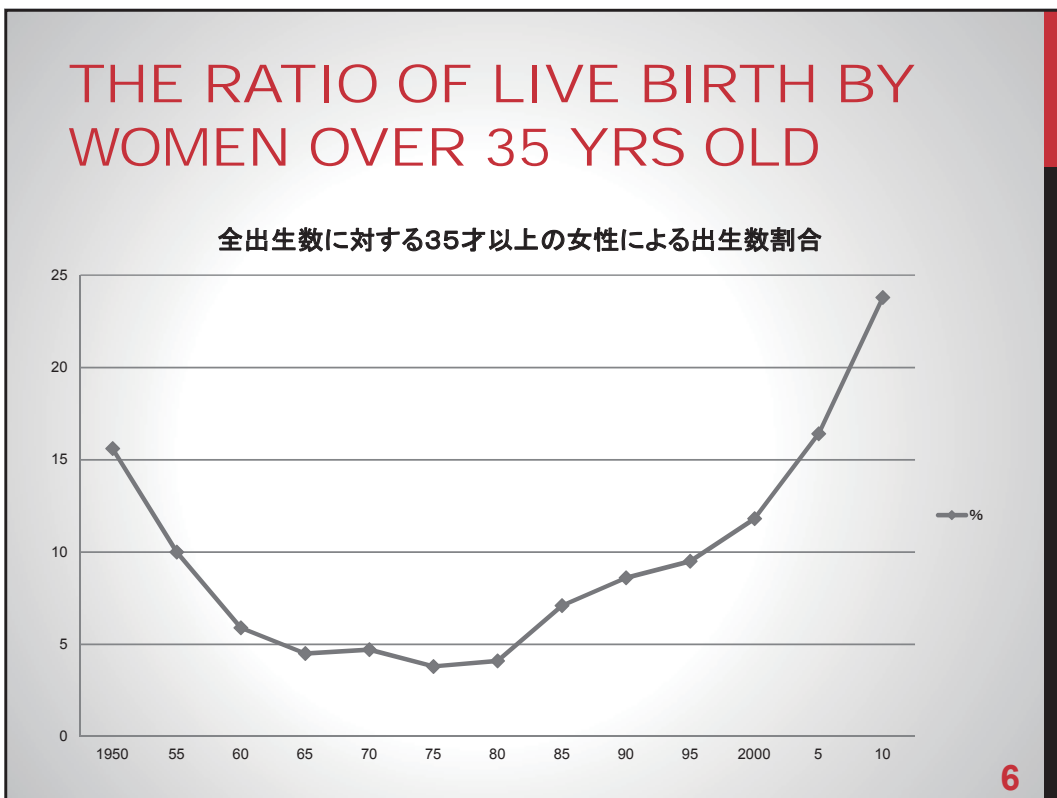
| Noninvasive + Not definitive  | Invasive + Definitive  |
|---|--|
| <ul style="list-style-type: none"><li>• <b>Ultrasound</b> scan</li><li>• Maternal serum marker screening (<b>MSS</b>)</li><li>• Cell-free fetal DNA in the maternal blood (<b>NIPT</b>)</li></ul> | <ul style="list-style-type: none"><li>• <b>Amniocentesis</b></li><li>• Chorionic villus Sampling test (<b>CVS</b>)</li></ul> |

3





5



6

## THE GUIDELINE OF MATERNAL SERUM MARKER TEST BY THE MINISTRY OF HEALTH ISSUED IN 1999

1. A doctor does not need to tell a pregnant woman actively about the prenatal test using mother's body blood.
2. The doctor should not recommend easily the new genetic prenatal test which used mother's blood to a pregnant woman.

7

新出生前診断 慎重に  
安易な実施 社会に混乱

好調の血で使う出生前診断  
先行の独、相鉄義務化

十分な情報もこに判

安易な中絶 日本で顕著も

New prenatal testing should be introduced with caution. Practicing the test without consideration may bring social disruption.

Abortion without consideration may increase

8

## MASS MEDIA FEARS AN INCREASE IN THE NUMBER OF ABORTIONS

### Because

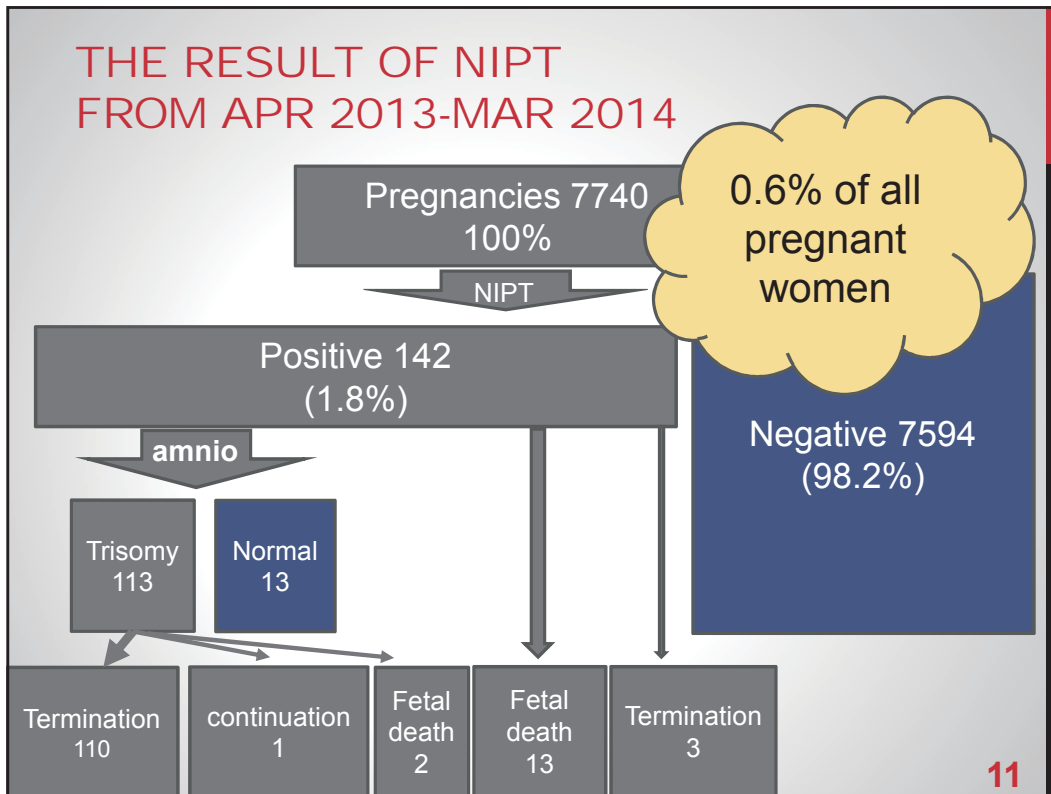
- 1. New prenatal test is non-invasive so that pregnant women choose to have tests easily or without consideration.
- 2. So results that show chromosomal abnormality of fetus should increase.
- 3. Therefore the number of abortions after the test would be increasing.

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## THE GUIDELINE FOR NIPT BY THE JAPAN SOCIETY OF OB/GYN (JSOG) IN 2013

- **The test should not be widely introduced into general obstetric clinical practice**
- **The test should only be carried out in pregnant women with an increased risk for fetal aneuploidy, conducting the test in mass screening of general pregnant women should be strictly prohibited.**

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### The Chronological View from the Criminal Abortion Law in the Penal Code to the Maternal Body Protection Law

|             |  |
|-------------|--|
| <b>1907</b> | Penal Code revised from 1880 It makes abortion severe crime.   |
| <b>1922</b> | Birth Control Movement, Margaret Sanger was invited to Japan.  |
| <b>1923</b> | A legal precedent to allow doctors to perform emergency abortion to save a woman's life.   |
| <b>1931</b> | Feminist (first wave) organized Japan Birth Control League and Alliance for Reform of the Anti-Abortion Law. Dr. Ogino, Kyusaku published his theory for contraception(Ogino Method) . |
| <b>1932</b> | Dr. Ohta, Tenrei invented IUD (Ohta Ring) based on Gräfenberg Ring in German in 1930.  |
| <b>1936</b> | IUD and contraceptive methods except for condom were forbidden.  |
| <b>1937</b> | Birth Control Movement was forced to quit. Ishimoto-Kato, Shizue was arrested for Birth Control expanding action.  |
| <b>1940</b> | National Eugenic Protection Law based on the Law of Nazi, Eugenic Sterilization  |
| <b>1948</b> | Eugenic Protection Law legalized abortion under conditions. However penal code of abortion issued in 1907 continue to operate.   |

**12**

| Japanese History concerning Prenatal Testing |  |
|--|--|
| 1950   | Reform of Eugenic Protection Law Women can have an abortion for economic (social) reason as well as her health reason.   |
| 1966   | A local government started the “policy of prevention of unhappy children.” It compensates partially cost of amniocentesis.   |
| 1973   | Anti-abortion movement scheme to delete the term of abortion by economical reason. Medical association demands abortion by fetus abnormalities. However, these amendments did not succeed because Disabled movement and women’s liberation movement are against it strongly. |
| 1974   | Disabled movement criticized the policy of prevention for unhappy children. So it was reformed.  |
| 1982   | Anti-abortion movement which demanded to delete the term of abortion by economical reason clause was again arisen. However, it failed to submit a bill to the Diet.  |
| 1996   | Reform of Eugenic Protection Law to Maternal Body Protection Law because EPL discriminate people with disabilities.  |

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Brochures published by the measure room to prevent that unhappy children in Hyogo prefecture around 1970

14





## Research Methods

Questionnaire and Interview in 2003 in Tokyo;

- 375 valid responses of Questionnaire
- 26 interviewees

**We started a bigger research project from 2013.**

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## Poster

IGSセミナー：キャサリン・ミルズ先生を迎えて（英語でのセミナー）

# CHOICE AND CONSENT IN PRENATAL TESTING

## 出生前検査における選択と同意

日本でも2013年4月より、新型出生前検査（NIPS）が導入されました。その導入にあたっては、安易な中絶につながるのではないか等、様々な議論がございました。本セミナーでは、オーストラリア・モナッシュ大学のキャサリン・ミルズ先生を迎えて、出生前検査と選択的中絶の問題について討論いたします。ミルズ先生には、オーストラリアにおける出生前検査と中絶の問題についてご報告いただき、明治学院大学の拓植あづみ先生には日本の出生前検査についてご説明いただきます。そしてお茶の水女子大学のデアウカンタラ マルセロ先生からは、この問題の法的側面についてコメントをいただく予定です。

### Speaker

キャサリン・ミルズ

**Catherine Mills, Ph.D.**

Associate Professor, Monash University, Australia

### 拓植あづみ

**Azumi Tsuge, Ph.D.**

Professor, Meiji Gakuin University

### Discussant

デアウカンタラ マルセロ

**De alcantara Marcelo, Ph.D.**

Associate Professor, Ochanomizu University

### Coordinator

仙波由加里

**Yukari Semba, Ph.D.**

Project Research Fellow, IGS, Ochanomizu University

### Program

- 18:15 Opening
- 18:20 Catherine Mills  
"Choice and Consent in Prenatal Testing"
- 19:20 Break
- 19:30 Azumi Tsuge  
"What do women want to choose in prenatal testing in Japan?"
- 19:45 De alcantara Marcelo  
"Comment"
- 20:00 Q&A and Discussion
- 20:45 Closing

\*セミナーは英語で行います。参加を希望される方は、お茶の水女子大学ジェンダー研究所の仙波由加里 (Semba.Yukari@ocha.ac.jp) までご連絡ください。

定員：先着 15 名

2015. **11.18** Wed. 18:15-20:45

お茶の水女子大学人間文化創成科学研究科棟 408 号室



主催：お茶の水女子大学ジェンダー研究所  
Organizer: Institute for Gender Studies, Ochanomizu University

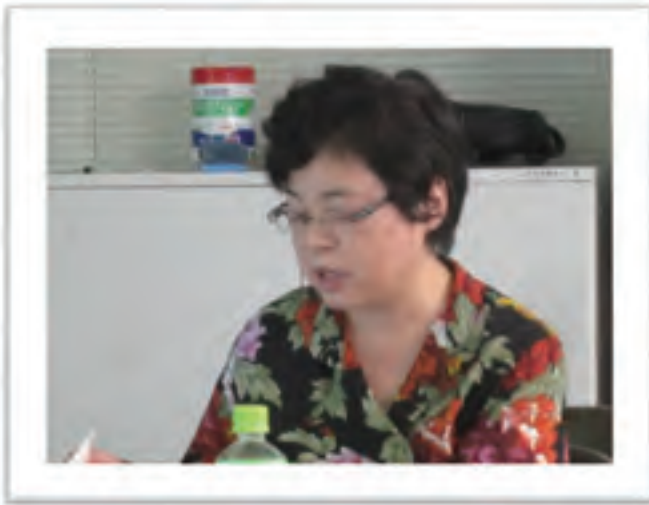
# Photo Gallery

**Seminar: Choice and Consent in Prenatal Testing**

November 18<sup>th</sup>, 2015

Room # 408, Graduate School of Humanities & Science Building











## IGS Seminar “Choice and Consent in Prenatal Testing”

—出生前検査における選択と同意—

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Institute for Gender Studies, Ochanomizu University

お茶の水女子大学 ジェンダー研究所

IGS Project Series 1

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Edited by Yukari Semba

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