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Achieving the desirable nation : abortion and antenatal testing in Colombia : the case of amniocentesis

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Chapter 6

The desirable child: amniocentesis and family life

By denying the human relations embodied in symptoms, signs, and therapy, we are not only mystifying them but also reproduce a political ideology in the guise of a science of (apparently) "real things" – biological and physical thinghood.

Taussig (1980: 3)

In the previous chapter I showed that amniocentesis produces two distinct types of patient: a foetus (at risk of) having a chromosomal variation, and a woman who is either at *risk of carrying* an undesirable foetus⁶⁶ or who has been *diagnosed with a malformation*. The woman is taken to be suffering from emotional distress due to the loss of the child she had envisioned, for it differs from the one she is carrying. Chromosomal and morphological variations are constructed within the medical environment of the Department as an emotional tragedy and a family disruption. Given these understandings, foetuses with Down syndrome and other chromosomal variations are envisioned by some medical doctors and prospective parents as being *incompatible with life*: not necessarily with the biological life of the future child, but in any event with the family life envisaged by prospective parents. In addition, in Chapter 4 I addressed the roots of what can be called a Colombian anthropological ideal, and the way in which the standards of normality imposed by obstetrics and by the close monitoring of the pregnant woman and the foetus resonate with such an imaginary of individuals and citizens.

In this chapter I focus on amniocentesis' incursion into family life, principally in relation to the kinds of ideal families that the availability of amniocentesis seems to render attainable. I argue that, given developments and changes in the functions attached to and

⁶⁶ In Chapter 5 I developed the notion of 'being at risk of carrying a foetus with Down syndrome' as the first moment in which women are considered and treated as patients. Furthermore, I explored the special emphasis that the condition of Down syndrome has within the context of prenatal chromosomal testing.

enabled by amniocentesis, and in combination with selective abortion de-penalisation (and the well established though previously unofficial practice of abortion), amniocentesis today responds to and enables the achievement of an imaginary of *desirable* offspring. This in turn derives from wider socio-cultural understandings of desirable individuals/citizens and families⁶⁷.

However, women and couples are not subjected to technological determinism. As an antenatal diagnostic technology, amniocentesis offers prospective parents control over their pregnancies in at least three ways. Firstly, it provides information to selectively choose the kind of children they are willing to rear. Secondly, it provides information with which to prepare for the kind of child they will receive, or that they will lose. Further, knowing this information can be framed as enabling prospective parents to be responsible towards their future children. Finally, by refusing the exam, parents can choose to experience pregnancy and parenthood as an event that, once it starts, must be allowed to run its course. This assumes embracing one's children as they are, rather than taking the view that prospective parents need or can be *prepared* for children with disabilities.

I present my argument by delving into what moves women and their partners when deciding whether or not undergo an amniocentesis, and how their interpretation of the exam shapes – and is shaped by – women's and their partners' notions and expectations of pregnancy, motherhood, parenthood, and family life. I conclude by arguing that exploring what moves women and couples when opting either for or against amniocentesis, in relation to the abovementioned notions and expectations, informs wider attitudes, discourses, understandings, and perceptions of people with disabilities.

⁶⁷ Before going any further, allow me a clarification about the way in which I address the foetus in the following chapter. Given that, for all women and couples that I met and that formed the foundation for this chapter, the foetus was seen either as their *baby* or their *child*, I too have kept such a conceptualisation of the foetus. I choose to do so since I explore women's and couples' relationship with and attitudes towards amniocentesis. To name the foetus as a *child* or *baby* does not relate to or convey my own understandings and conceptualisations of it.

Interpreting amniocentesis

This is my second child. I was very afraid about the exam, especially about the risks of losing the baby. I even had decided not to take it, but then my gynaecologist explained to me that the risk is very, very low and said that it was always better to know (Natalia, 40 years, designer and housewife).

Natalia was perhaps the only woman older than 35 years of age who hesitated so much about having an amniocentesis. This pregnancy took her and her husband by complete surprise. Their first child was the product of IVF treatments, after long attempts to conceive. With the success of IVF, Natalia and her husband thought that they were done with reproduction. After the birth of the child she decided to quit her job as a designer and spend as much time as possible with her son. The life she had chosen to live was a family life. Although not disruptive to her family routine, this second pregnancy came as a surprise and Natalia and her husband experienced it as a gift; hence Natalia's hesitation to undergo amniocentesis. Natalia and her husband's biggest fear was the risk of miscarriage that amniocentesis carries. Although they agreed with her doctor that it was best to know how the baby was, to make sure it was alright, they were not completely sure about the trade off between information gained on the one hand, and the risk to the baby on the other. After a persuasive meeting with her gynaecologist, in which they were reassured that the risk of miscarriage *'was very little, nothing to worry about'* as Natalia explained, she and her husband opted for the information, because, in Natalia's words, *'it is better to know in advance'*, emphasising the role and authority that she conveys onto her gynaecologist.

Clinically, Natalia belongs to two groups: an *age* group, and a group of *high risk pregnancy*. She is older than 35 years, and has a history of multiple miscarriages and difficulties becoming pregnant. Usually women and couples in either of these groups are less doubtful than Natalia about having an amniocentesis, and her hesitation called to my attention the different understandings of amniocentesis.

With regard to the age group, for most women the risks of miscarriage involved in an amniocentesis are out weighted by the perceived value of the information it provides:

that is, ruling out Down syndrome. But even though this group of women have in common the search for Down syndrome, not all interpret and experience amniocentesis in the same way, as I show below. As for the women labelled as being in a *high risk pregnancy* group, amniocentesis is commonly perceived as a routine, compulsory test that will somehow ensure a healthy pregnancy outcome, as Press & Bowner (1997) have reported is frequently the case.

The 'aged pregnant'⁶⁸, women who fall into the category of a *high risk pregnancy*, and those whose early ultrasound examination show foetal morphological variations, are all rather determined in opting for amniocentesis. However, their motivations for and interpretations of amniocentesis tend to differ from one group to the other. Furthermore, despite their promptness in opting for an amniocentesis, the large majority arrive at the exam fearful, regardless of whether they are (apparently) sure about aborting – or not aborting – a malformed foetus; or on the contrary, are unsure about whether to consider abortion dependant on amniocentesis results. All the women and couples that I accompanied to the amniocentesis cried beforehand, and many during and after the amniocentesis as well. As I mentioned in Chapter 5, they cried not necessarily out of pain, but out of concern for harming their baby, or out of anguish at the possibility of having a baby with a chromosomal variation. We could say, however, that what moved these fearful and concerned women and couples to overcome their fear was, again, the perceived value of the information that amniocentesis provides, in relation to what such information would allow them to do with the specific foetus.

Not all women and couples who are offered or presented with the possibility of having an amniocentesis opt to undertake it. However, although they may be as determined and sure about their decision as those who do go for the exam, women and couples who opt *not* to have an amniocentesis also express their motivations in multiple ways.

When I started conducting fieldwork I first thought that what formed the basis for these two groups (those who undertake an amniocentesis and those who do not) were ideas and convictions held about selective abortion. However, such a way of thinking soon proved to be over simple. Although a minority, some women and couples undertake amniocentesis

⁶⁸ That is how women above the age of 35 are referred to by physicians.

because they consider it paramount to know the health status (in this case in chromosomal terms) of the foetus, so they can either start to prepare themselves for the imminent death of their child, or they can start to prepare themselves for the arrival of a child with disabilities. For these women and couples, the possibility of abortion is not the (main) motive for their choice. Further, not all women who opt out of amniocentesis do so because they reject the very idea of abortion. Though some do, others prefer not to risk a specific pregnancy that has a particular value, in exchange for information that they do not deem sufficiently relevant.

In order to understand what moves women and couples to decide whether or not to opt for amniocentesis, I suggest grouping women according to criteria other than their clinical categories, or the rigid opposition between those who undergo the amniocentesis and those who prefer not to. In order to elucidate the incursion of amniocentesis into family life, in relation to women's and couples' motivations for undergoing amniocentesis, I define three groups of amniocentesis users and two groups of non-users, as follows. Among those who opt for amniocentesis we firstly find those who see in amniocentesis a tool for selectively aborting foetuses that they are not willing to rear – for whatever reason. Secondly, there are women and couples who see in amniocentesis a tool for controlling their lives, in the sense that they will not be taken by surprise but will be emotionally and logistically prepared for the arrival of a child with disabilities, or will be prepared for the eventual death *in utero* of their child. Finally, there are other women and couples for whom amniocentesis is simply another antenatal exam; one that will clarify a diagnosis and will bring some order to their ordeal, whether because the ultrasound examination showed a foetal morphological variation, or because the woman tested positive for toxoplasmosis. This group tends to rely on amniocentesis as a source of further information that will help clarify the current panorama of uncertainty, and will provide knowledge for determining a possible course of treatment that will cure or better their child's health status. Given the qualities of each of these groups, I propose to call them *selection*, *preparation*, and *possibilities and responsibilities*, respectively.

On the contrary, those who opt out of amniocentesis could be clustered as those who, given their religious affiliations, are openly and irremediably at odds with abortion under

any circumstances. Secondly, there are also those women and couples for whom this specific pregnancy is more important than the possibility of knowing if the foetus carries a chromosomal variation. For people in this group, children with disabilities are not perceived as a burden one might want to spare oneself, and furthermore, these women and couples find it ethically and morally inadmissible to choose to abort a foetus based on morphological or chromosomal variations. I call both groups *child versus information*. In what follows I will address each of these four groups.

Having come to this point, allow me a word regarding the participants that make up this chapter. Not all women who are presented with the option of amniocentesis in practice have access to the exam, and what limits access relates to economic constraints. As addressed in Chapter 3, amniocentesis is an expensive procedure, not covered by the Obligatory Health Plan or by pre-paid premiums. Therefore, only the limited number of better off women and couples (or those who collect or borrow money from relatives, friends, or even bosses) can decide to have an amniocentesis. That is why most of the 22 women and couples I encountered during fieldwork, and with whom I spent long waiting hours, had multiple phone conversations, and held various interviews, were in the vast majority highly educated, and also had the means to *choose* for or against amniocentesis. The women and couples I have chosen to give voice to here are those that, out of the 22 cases, I consider make up and account for the spectrum of possible understandings of and functions attached to amniocentesis.

Those forced out of consideration of the exam are many. However, I will not elaborate any further on the matter than I have already done in Chapter 3, in the sub-section addressing social justice in relation to who is *human enough* to access a technology that enables the exercise of human rights regarding sexuality and reproduction, and the human right to free of inhuman, degrading and cruel treatment, and torture⁶⁹.

Increasingly, pregnant women are making use of antenatal testing technologies to gain knowledge about their babies' health status. Routine antenatal care may include

⁶⁹ See Sentence C-355/06.

sonograms and foetal checkups, at least once every trimester of the pregnancy. Amniocentesis is an additional such technology. Scholarly interest in the factors that motivate women to undertake amniocentesis, whether offered by the gynaecologist or requested by women themselves, emphasises that decisions regarding acceptance of amniocentesis are informed by individuals' life trajectories and cultural backgrounds (c.f. Rapp 2000; Brookes 2001; Browner & Preloran 2004; Hunt et al. 2005). Such studies have illuminated the ways in which amniocentesis challenges previous – and enables new – definitions of antenatal life and pregnancy. From such a body of knowledge, two main aspects that inform women's choices about amniocentesis can be highlighted. Firstly, the understanding of what amniocentesis entails and the sort of information the test provides. This point is coloured and shaped by the medical encounter in which amniocentesis is presented (whether by a geneticist or gynaecologist). Secondly, the decision to opt for amniocentesis is also informed by women's and their partners' position towards abortion and their experience with disabled children (c.f. Rothman 1978; Marteu & Drake 1995; Press & Browner 1997; Mitchell & Georges 1997; Rapp 2000; Brookes 2001; van der Berg et al. 2005; Amhed et al. 2006).

Selection

*Down syndrome is an incompatibility with life;
with my life (Juana, 42 years, architect).*

For the majority of women and couples in this study, amniocentesis is interpreted as a source of information that helps them match up, at least momentarily, their life plans and parenthood expectations with their actual pregnancy. Amniocentesis is perceived as and used for providing the means for choosing the kind of offspring women and their partners are willing to rear. For these women and couples, amniocentesis use for abortion ends is rather self-evident. The clarity with which women and couples talk about abortion reveals the minimal interest that many prospective parents have in raising a child with a disability.

Moreover, it is surprising the acceptability that aborting a foetus with Down syndrome has among some women and couples:

I'm having an amniocentesis because I need to be sure that this baby does not have Down syndrome; you know at my age the risk is higher and I do not want to have a child with Down syndrome. I am not ready for having a baby with Down syndrome (Juana, 42 years, architect).

I know I can abort, and I will if the exam [amniocentesis] says my baby has Down syndrome or something like that. I do not want to have such a baby, why would I? ... I know I can abort if my baby is sick. It is incompatible with life. You know how difficult life is for people with disabilities, and I do not want my baby to suffer that. I also do not want to suffer that myself [mothering a child with Down syndrome] (Omaira, 41 years, seller of office supplies).

I never doubted about amniocentesis. I mean, if there is this exam that tells me if the baby is right or that he has the Down's disease, well I want to have it ... I'm pretty sure I do not want to have a baby with Down (Cilia, 42 years, computer scientist).

I'm 43. I already have a 13 year old son, so if this one has Down Syndrome we are not going to have it (Lina, 43 years, lawyer).

But the willingness for selective abortion does not only concern cases of foetuses with Down syndrome. In general, prospective parents are disposed to abort foetuses with chromosomal variations of other kinds as well:

They say the baby is too short for the time [age] she has, also they found that the umbilical cord is missing one artery, and that the baby has something in her little head. So the doctor [Dr Rincón] says that these may be related to a problem with the chromosomes, something like trisomy-18 or -13, or a Dandy Walker or something like that (Eliana, 32 years, accountant).⁷⁰

⁷⁰ Dandy Walker is a brain alteration; in the case of this foetus it meant the absence of part of the cerebellum. In many cases, Dandy Walker is associated with chromosomal alterations. For a complete description see Harper et al. (2007).

I do not want to have this baby with a cleft lip and palate ... I needed an amniocentesis so they can confirm a trisomy [13 or 18] and so I can abort it ... with that trisomy they will do me the abortion (Elsa, 36 years, industrial engineer).

From the quotes above one can see that for these women and couples, parenthood is neither understood nor experienced as an event that takes over one's life but, on the contrary, that one chooses to accomplish according to one's own standards of family and individual life. However, women and couples who interpret amniocentesis as a means for choosing the kind of offspring they want to have, often are in quite dissimilar situations from one another when confronted with the possibility of karyotyping their foetuses.

The latter two quotes above demonstrate cases in which there is a different relationship with and experience of amniocentesis to the other women above the age of 36, who are considered *at risk* but have no confirmed morphological variation. Although in both groups the women and families tend to experience amniocentesis with anticipation and anxiety (as was the case for all who undertook an amniocentesis), the existence of a previously diagnosed alteration imprints a reality and factualness on the experience of the amniocentesis process. Hence reflections on the possibility of having an abortion are also more elaborated and more pressing than among those for whom abortion is a thought but not yet a potential reality.

In any situation there is a gap between *thinking about* aborting a foetus and *choosing to* abort a foetus, and that difference is a process that gains shape in the period of awaiting amniocentesis results. On average, this waiting period lasts 22 days, in which major events take place, for example some women feel the baby move for the first time. Throughout this time women, their partners, and close family members live in a sort of limbo in which bonding with the foetus takes place, even though the phantom of the possibility of a chromosomal variation haunts them continually. Thus, bonding with the foetus does or may take place, but it is bonding with restrictions. This was visible when I phoned women and couples during the waiting period:

I want to see the results now; I can't sleep, I want to know that my baby is alright, so I know what to do [referring to abortion] (Juana 42 years, architect).

We have to wait and hope for the best ... what else? ... But the results just take so long ... we are like in the middle of the desert. We need to know what we will do (Eliana, 32 years, accountant).

We keep busy, working a lot so we don't have much time to think. We just hope that the baby is alright. But we already talked to Dr Sossa and he knows that if the baby has Down syndrome we will not have it (Lina, 43 years, lawyer).

As mentioned before, for women and couples who belong to this group, the question of abortion is self-evident when they are about to have an amniocentesis. In that sense, the idea that amniocentesis provides information for choosing the kind of offspring one is willing to give birth to was rather well accepted and generalised amongst the pregnant population with which I was in close contact.

This is also the case for many other people I encountered whilst conducting fieldwork (i.e. friends, relatives, and the many taxi drivers who drove me from one clinic to another on a daily basis), who held the opinion that amniocentesis' main function is to provide foetal information upon which prospective parents can make a reproductive decision; that is, to have an abortion should the results show foetal chromosomal variations. The recurrent question that I was asked by women, couples, and random people was: *why would anyone want to bring up a child with disabilities?* Amongst the arguments people offered surrounding that question was the reference to life being unjust to people with disabilities, the shared imaginary that they live sorrowful lives, the conviction that people with disabilities suppose an extra economic and emotional burden on families, and the negative depiction of them as simply unwelcome individuals with limited life chances. Women, couples, and random people, regarding the use and functions attached to amniocentesis, spoke eloquently about the generalised attitudes about and level of intolerance towards rearing, living with, or having contact with people with disabilities in Colombian society.

However, in order to study amniocentesis as a technology that enables women and couples to choose the kind of children they are willing to rear, it is important to pay attention not only to attitudes towards selective abortion, but also to the practice of it. In other words, we need to pay attention to the moment in which amniocentesis positive results arrive and a decision has to be made (either to abort or not); and then the moment in which the *thought* of abortion becomes a *decision*. There is a major difference between the two. In the former instance the technology disrupts the pregnancy and renders it *sad*; in the second instance it disrupts the pregnancy by initiating a process that might lead to its termination.

As tempting as it is to follow the easier road of focusing on discourses and social imaginaries – as eloquent as they might be – I propose to follow a more nuanced path, analysing amniocentesis through its interpretation as a tool for choosing desirable offspring.

In order to do so I present two cases in which selective abortion did take place after the confirmation of a foetal morphological variation. These cases help illustrate the spectrum of reactions regarding a positive foetal diagnosis. The first case is the story of Elsa, a woman who was moved to ask for an amniocentesis after specialists diagnosed her foetus with a cleft lip and palate. Amniocentesis results turned out to be positive for trisomy-13, considered by specialists in the Department as an incompatibility with life. The second case I want to bring in is the story of Eliana and Carlos, a couple who chose to abort their foetus who had a variation in the cerebellum, but for whom amniocentesis results turned out to be negative for any chromosomal variation.

From cleft lip and palate to trisomy-13: Amniocentesis as a green light

According to Daniela, one of the nurses in the Department, 35 year old Elsa visited the Department for the routine 11th to 14th week ultrasound check up⁷¹ in mid September:

⁷¹ The purpose of each check up performed at the Department of Maternal and Foetal Medicine and Care is discussed in Chapter 5.

They were examining her; all was going fine until I noticed they were taking too long in dictating to me the facial features. I, of course, had no idea of what was happening ... But then, I knew there was something wrong because they were going over and over and over again over the baby's face and they were discussing in technical terms about the lip; then I knew what was wrong. Finally Dr Sossa told the lady – *Yes, the baby has a cleft lip and palate ...* You won't imagine her reaction – well you know how it was. She started crying and crying and saying that she did not want to have that [baby], she was insisting a lot that she wanted to have an abortion, that she did not want that child, so we had to call Jimena [the psychologist] and she came and tried to calm her down but all she wanted was an abortion. Then Dr Sossa was very clear; he told the lady that he will not do an abortion for that [cleft lip and palate], that that has surgical solutions. But she kept crying and asking for an abortion.

Elsa left the Department still crying and visibly unhappy with the situation she was going through. She was unwilling to give birth to a child that did not respond to her standards of normality. She refused to mother a child with what she found to be a terrible physical malformation; for her, the foetus she was carrying became '*a horrible thing*' that she wanted to '*get out right now*', as she expressed. But for Dr Sossa, a cleft lip and palate does not constitute a strong enough reason for granting an abortion, and so he denied the procedure. After Sossa's negative response, Elsa also tried with Jimena to frame her desire to abort the foetus with a cleft lip and palate in terms of risk to her mental health status: '*No, I cannot have this child, I just cannot cope with this*'. But this argument did not convince Jimena, who saw in Elsa a woman who could handle the physical difference of her child-to-be, but who did not want to face the world mothering a child like the one she was to deliver. Thus, after the psychological evaluation, Jimena did not find any element that could indicate possible harm to Elsa's mental well-being. At that stage, Elsa could therefore not access a legal abortion.

But days later, Elsa returned to the Department to schedule an amniocentesis. She had talked with a gynaecologist and a lawyer, and knew that in order to have the abortion granted she would need a further foetal diagnosis, for instance the presence of a trisomy. Elsa underwent the amniocentesis. During the time in which she awaited the results she yearned for a positive result that would allow her a green light to abort the foetus (that would be a child that she already disliked profoundly). 21 days after the amniocentesis took

place, the results arrived with a positive diagnosis for trisomy-13. Elsa was the only woman that I met who was visibly happy with the variant chromosomal status of her foetus; she was glad to receive a positive result. That same day Elsa was given the medicines for inducing the abortion, and on the 18th of October her foetus came out of her body and was sent to pathology.

In this case, amniocentesis was interpreted by Elsa as providing a strong enough argument to grant her the right to abort a foetus that she did not want to rear. The perceived stigma that people with a cleft lip and palate suffer, as well as the outright rejection of giving birth to a child that was not seen as *beautiful* – or at least as *normal* – formed part of the rationale that Elsa made use of when reflecting on her decision. But *luckily* for Elsa, trisomies are considered by gynaecologists and specialists in the Department as constituting an ‘incompatibility with life’, hence such cases fall into the category de-penalised by the Constitutional Court.

Paloma: Or the stupid sister

I will now bring in a second case in my analysis of amniocentesis as a tool which enables families to choose the kind of offspring they want to bring up. This case is a family which, although from the beginning voiced their willingness to abort the foetus should an anomaly be confirmed, found that the decision, process, and aftermath of aborting such a foetus was not at all easy.

Paloma was the name that Eliana and Carlos had given to their baby. They told me Paloma’s name the day we met after Eliana had had the abortion of the 28 week old foetus, which was first suspected to have a trisomy-18 or -13, but later turned out to have no chromosomal variations. However, the foetus had a morphological variation of the cerebellum, and other conditions were suspected in relation to the heart and the brain. We met a week after the abortion had taken place: Eliana and Carlos came to the Department to talk with me, and were supposed to see Jimena, the psychologist, but Eliana had doubts about that meeting. *‘I don’t want people to start asking why I did what I did, she is going to start*

asking things and I don't want that'. During our talk I saw Eliana and Carlos without that intense look of worry and sadness that they had both previously had all the time in their eyes. The trouble was somewhat gone, though the sadness remained latent in Eliana's eyes. Carlos, on the other hand, was talkative and seemed relieved that the experience of being diagnosed (as a couple) with a foetus with a morphological variation was over.

That day we had a meeting at 9.00 a.m., but they arrived more than an hour late. They explained to me that they were in the cemetery collecting Paloma's ashes, for her body had been cremated on Monday that week. I asked Eliana how she was feeling and she answered: *'Sad but relieved, the baby was worse than they had told us'*. However, the pathology report showed that from the many conditions diagnosed to the foetus, only a missing part of the cerebellum was present. The consequences that such a missing part would have on the future child are unknowable and unpredictable antenatally. Eliana recounted for me her abortion experience, which she framed in terms of having a miscarriage. She told me how after the delivery she asked the nurses to pray with her for the soul of her baby, how she asked the nurses to dress the baby with the clothes they had bought for her, and how she had held her baby to say goodbye. *'Her little head was indeed bigger than usual'*, added Eliana after a moment of silence and tears. *'It is good that we did this [the abortion] and maybe later we can try and try and maybe we are lucky and have a healthy child'*, explained Carlos. Then Eliana turned to me and asked, more to herself and to Carlos, *'...and what if not?'*

During the amniocentesis and diagnosis processes, Eliana showed uncertainty about having an abortion, something she usually expressed when she was alone. For the two long months that the process took, she battled back and forth making her mind up regarding an abortion of the wanted and sought after child, found to have morphological variations. The first time we met, a cloudy morning in June whilst she was waiting for her amniocentesis, Eliana cried while telling me that her baby was not as the doctors expected her to be.

During this first encounter, Eliana mentioned two issues that caught my attention. Firstly, she repeatedly said that they had tried for quite some time to get pregnant again, as they really wanted to have more children. But although she loved this child a lot and they were looking forward to having more children, she did not want to have this particular one. Secondly, Carlos and she had decided not to tell anyone about the condition of the baby:

Because you know how people are, and they will start judging us because our baby is not normal ... You know how people think that when a baby has a defect or something they say that it is because the parents had sex whilst being drunk, or in a wrong way.

I never asked Eliana what she meant by '*having sex in a wrong way*', but her worry that her and Carlos' behaviour was going to be judged based upon their child's appearance explained to me why her major preoccupation with the foetus' condition was that it could be visible on the outside, that people could tell that the baby had '*something wrong*'. Such a perception of a (future) child with disabilities indicates that the language of the chromosome, and associated biomedical languages, is not necessarily the dominant language for women and couples. Actually one could say that they are competing discourses that might work together or clash when confronted with a foetal morphological or chromosomal variation.

In all our meetings and talks over the phone, and when visiting the specialists at the Department, Eliana placed stress on the future baby's appearance. Hence the remark she made regarding the big head of Paloma after she was born, which was not especially different from other foetus' heads of the same age as Paloma at the time of the abortion.

When in June Dr Rincón told them about the possibility of a trisomy-18 or -13, or a Dandy Walker, Carlos and Eliana started to read all about such conditions. Both are professionals and were interested in having as much information as they could for making an informed decision. Thus Eliana and Carlos knew quite well the possible consequences of either of the conditions. After the amniocentesis results turned out to be negative, the medical staff and the prospective parents focused on the cerebellum. And yet, even though the science and technology of antenatal life has advanced enormously, it is still impossible to predict the level of cognitive *capacity* that a person diagnosed with either a chromosomal condition (including Down syndrome) or any kind of cerebral variations will show. This latter point – the point of the unknown – was the breaking point for Carlos and Eliana (and many other couples too) in making up their minds and opting for an abortion. As the

psychologist Jimena Estrada expressed in a medical meeting, couples abort fetuses moved by the uncertainty regarding the future child's cognitive capabilities:

Parents do not want to face uncertainty, so in the presence of a possible cognitive or mental condition parents prefer to abort, as it happened with Eliana and Carlos.

Given Eliana's hesitation about the abortion, Dr Sossa was initially rather unwilling to grant it: *'I feel he [Carlos] is pushing her. She is not ready for having an abortion and if she has one now it will be devastating for her'*. To a great extent that was the case, in the sense that Carlos was positive and clear about not having this child. Carlos was much more certain about having an abortion than Eliana was, and he had a rather articulated explanation for his position. The way in which he framed his position showed a caring father and a caring husband who was doing what he thought was best for his family. But he was also imposing his will. Although he wanted more children, he perceived that having this particular child would pose a great burden on them as a family and as individuals. Therefore, he had to step in and take care of his family by choosing, and many times pushing, for an abortion:

You know my job, I am out on missions very often and my job is extremely dangerous [Carlos works for a Military Police division, of which the main task is to look for and rescue people who have been kidnapped by illegal armed forces]. I know when I leave for a mission but I never know if I will come back. I cannot leave Eliana this responsibility of a disabled child. Imagine I get killed and Eliana is left with two children and one depends entirely on Eliana. Besides, if we have this child, Eliana will have to quit her job to take care of the baby with problems. Do you know how much effort it cost Eliana to be where she is? She has worked extremely hard for having a career and now she will just have to throw that away for what? For taking care of this child? No, we rather not have her [the child] ... Imagine Eliana has to quit her career and then imagine I get killed in the jungle or in the mountains while I'm out on a mission. What will happen to my family? I have to take care of them ... But also, more than those reasons I just gave you, I also think of Oriana my daughter [11 years old]. To bring that child will be also to give Oriana a big responsibility that she has no reason to bear. It is not only us [Carlos and Eliana], Oriana will suffer as well because of this decision of letting this baby be born. She has her friends and she does not need to be the one with the

stupid sister. You know this world we live in, the baby can be blond and blue eyed, but what will define her is her problem and Oriana has to be the one to play with her and be ... well, as I say, the one with the stupid sister ... I cannot do that to my girl.

Carlos' account for his position towards the abortion of the foetus they later called Paloma is extraordinarily eloquent. It not only sheds light on what are the expected (gender) roles that he and Eliana have and would have should they bring the pregnancy to term. But this narrative also tells us about how, in Carlos' view, this future child with a disability represents a disruption to the family life he had envisioned and that he is experiencing now. Further, it shows how – regardless of compliance to the strict (foreign) beauty (and *racial*) cannons to which Carlos referred, and which resonate with the wider Colombian imaginary discussed in Chapter 4 – people with disabilities – cognitive disabilities to be more precise – are understood and defined by those characteristics alone throughout their lives. Beauty, other abilities, and other characteristics that a person with cognitive disabilities may have are erased from the frame that contains the person: *'she will always be the stupid sister'*. Eliana shared Carlos' understanding of the ways in which bringing this pregnancy to term, and thus bringing up a child with cognitive disabilities, would affect their family dynamics and individual aspirations. But in addition, for Eliana facing the world with a child with cognitive disabilities and physical variations was an idea that haunted her and prevented her from telling people about her baby's condition:

So we [are] spared the gossip. People always judge when your child is not normal ... they would point at us and we have not done anything wrong. Although this could have happened to anyone, you know? This is an accident and no one chooses to have an accident, but people do not know that and they judge and gossip.

In sum, for Carlos a child with disabilities represented an extraordinary disruption to his family in terms of dynamics and status. In Eliana's last apologetic quote, the burden is aggravated by the shame that having a child with disabilities would bring on her, and by extension, her family. But despite their articulated decisions for aborting, the aftermath of

this particular abortion shows that, although the family regarded the abortion as their best option, it did not lessen the pain of losing a child.

When we met after Eliana and Carlos had collected Paloma's ashes from the cemetery, the couple asked me to walk with them to their car. Whilst I was saying goodbye to Eliana, Carlos pulled out of the car a small transparent zip lock bag: '*Look doctor, this is our baby*'. Without any preparation I was handed the ashes of a small body, in which femurs, some ribs, and some parts of the skull were still visible. It took me a couple of seconds to react to what was happening. I had shared with them moments of sadness and uncertainty; I had spent hours on the phone with Eliana; I had accompanied them during the long waiting hours; I was present during the amniocentesis, the emotional therapy, several ultrasound check ups. In a word, I had bonded with this family, and now I was being made part of the process of making sense of the loss of their child, and of the decisions that lead to such an event. Through the materiality of the body of the foetus they had called Paloma – who they decided to abort but referred to as a miscarriage; who was a sister to Oriana, a girl who experienced the death of her baby sister with deep sorrow and who was going to be given some of the ashes so she could have a sister to play with – Eliana and Carlos were coming to terms with their decision. In that dark and packed clinic parking lot I was part and witness of a process of coming to terms with an expected and wanted child that had become unwanted; and yet it was always felt as a child and therefore her remains were treated as the remains of a family member.

I must accept that to be part of that process, to have shared the experience of looking at the ashes and tiny bones of a foetus whom I had seen in ultrasound check ups, as a piece of paper in the amniocentesis results, as a dead body pieced out by pathologists and shown to all those present at the medical meeting, was an extremely difficult and painful experience. However, that experience allowed me to understand that abortion decisions are not easy decisions. Furthermore, choosing to interrupt a pregnancy does not necessarily mean to re-interpret what was felt as a *child* into the term *foetus*. Although it was a conscious decision not to bring this particular child into the world, Paloma and many other foetuses remain children – dead children – to their parents.

Preparation

I had the amniocentesis because I wanted to know in advance how the baby was ... I think that to be caught off guard is pretty horrible (Ema, 40 years, M.D.).

As Hunt et al. (2005) suggest, women and couples also tend to accept the offer of amniocentesis based on what they consider to be the benefits of the exam, namely, the possibility to know and be sure that their baby is healthy. Or as Mateu (2002) highlights, some women may fear, either because of their family history, age, or other life events (e.g. exposure to long medical treatments, X-Ray and such), that their baby might have a chromosomal variation. Amongst such women and couples, amniocentesis is interpreted as a source of control over their lives, yet a different form of control than with the group presented above. The women and their partners whom I have clustered in this *preparation* group opt to undergo amniocentesis with anxiety and anticipation as most women do; wishing that the amniocentesis results turn out negative (bear in mind Elsa's case as an example of an exception). However, what I found to be particular about this group was that for some of these women and couples, the exam was seen as valuable in relation to the information that it provides, since that information is perceived as helping them figure out how to prepare themselves for the arrival of a child with disabilities. For these women and couples, the possibility of abortion is not what moves them to undergo an amniocentesis:

I got pregnant when I was 40 years. So I know I have an incremented risk of having a child with Down Syndrome ... But I also know that the apparent incremented risk is just that, apparent. What happens to the statistics is that fewer women older than 35 get pregnant, so it seems to be an incremented risk, but really, a young woman has, relatively, the same probability I had ... But I knew I had this risk and I knew I also had to face the other risks [amniocentesis' risk of producing a miscarriage]. We both agreed with the exam [she and Pablo, her husband] and it was a rather easy decision. I know that for some women it is a tough decision because of the risks but we preferred to know if the baby was alright. The idea of abortion, of actually

having an abortion, was kind of out of discussion. I mean, by the time you receive the results is already the 20th week, an abortion at that time is very dangerous for the woman ... and we can even discuss if we can call that an abortion. You undergo the amniocentesis to know and to be prepared for what will come (*lo que a uno le espera, porque qué más?*), because what else ...? But really, I think that the issue of selective abortion is very difficult because how can you choose who can live and cannot? Besides, an abortion after the 20th week ... I mean that is quite far in the pregnancy, it is not like I was fecundated just three hours ago ... But we wanted to know, so we could be prepared, somehow (Ema, 44 years, M.D.).

I must say that Ema's account of the amniocentesis was given in retrospect. I also must say that I have known her for many years and it was through her and her husband that I got to know of amniocentesis in the first place. She had the exam 4 years ago, so her account is more a reinterpretation of amniocentesis and of her experience. I cannot speculate on whether her perspectives on selective abortion would be different should she have an amniocentesis today. I also could not tell what she would have done had the results turned out positive. That is a question she herself does not want to answer:

I cannot tell you what I would have done should the baby have had something wrong. I think you only know when you go through that. I can imagine it would be painful, but I can also imagine that I would have had the baby.

Furthermore, the point of abortion is difficult to raise, perhaps pernicious even, since during the lengthy conversation we had her son, Martín, played besides us. Her account of amniocentesis today, about selective abortion, about what she would have done if the amniocentesis results had been positive, were issues that related directly to this playful, good looking, happy child who, four years ago and in the form of a foetus, had his chromosomal count examined. So, all her experience of amniocentesis and her account for it is crossed and coloured by her experience of mothering that very child that underwent the exam.

At a personal and a methodological level, the experience of linking amniocentesis with a child whom I have known since he was born, whose amniocentesis report I saw when it was ready (four years ago – the first one I ever saw), and who has felt in many senses to be the same being in all the different stages in which I have met him, was hugely important. That act of experiencing the link between the past and the present in one same person helped me understand amniocentesis differently. In more real terms, it helped me to visualise the consequences, or rather the potential, of having a source of information such as amniocentesis; although I must accept that the experience of reflecting about amniocentesis and its links with selective abortion, whilst Martín was playing puzzles next to me, was rather surreal.

It is not only women and couples who think retrospectively about their motives for using amniocentesis who point out the potential the exam has for helping them to be prepared for the arrival of a child with disabilities. And for others, amniocentesis also proved to be a good source of information for preparing themselves for the loss of their child. Such was the case of Claudia and Javier, two medical doctors for whom the information provided by amniocentesis allowed them to prepare themselves for the imminent (in utero) death of their second child. Amniocentesis, in combination with ultrasound follow up, disclosed information about the delicate health status of the foetus. For this couple and their close kin, the experience of knowing the looming death of their child meant enormous suffering. But knowing about it meant as well the opportunity to be parents, albeit for a short time, of the baby they were expecting.

This is my second amniocentesis ... In my previous pregnancy, around this time Dr Rincón found a possible trisomy-21 ... so we had the amniocentesis. But when that diagnosis was confirmed Alejandro [Dr Rincón] also found that the baby had hydrops fetalis⁷² ... We knew the baby was going to die. And he did, it was all very sad ... But the positive side, if there is any, is that we could be with him [the baby] till he died. We cared for him as much as we could. He was our baby, you know? And we treated him like that ... we loved him very much. In every follow up Alejandro [Dr Rincón] explained to

⁷² Hydrops fetalis is a foetal condition characterised by the accumulation of fluid in two or more body areas. For further elaboration of this condition see Abrahams et al. (2007).

us how the baby was doing and in that way we could get prepared for his death ... (Claudia, 35 years, M.D.)

This time, Claudia and Javier asked Dr Rincón to perform an amniocentesis. Despite Dr Rincón's assurance to the couple that he could observe no indications that a chromosomal or morphological variation was endangering the life of the foetus, Claudia and Javier needed to know how their baby was.

Well, the previous experience was very difficult. This time, again we want to know and to be sure about how the baby is. I'm less anxious this time than the previous one, Alejandro says that he sees the baby in perfect condition. But we need to know. I pray to God every day that everything is alright (Claudia, 35 years, M.D.).

What links Ema and Claudia⁷³ to one another is that amniocentesis indeed helped them to partake in their reproductive lives at a more 'objective' level in order to feel better prepared to deal with misfortune or with loss, while at the same time allowing them to feel love and anxiety for their future baby. Having an amniocentesis, in addition to other activities such as eating healthily and abstaining from alcohol or smoking, enabled them to actively engage in preparing themselves for what they thought life with a child with disabilities would be like; or, in the case of Claudia, by being able to mother a child for as long as she could before the child died in her uterus. In other words, for these as well as for the women in the previous group, reproduction is not experienced or considered as an event that takes over one's life, but as an event in which the woman, and sometimes her partner, can partake. Contrary to the first group, however, the way in which these women enhance their engagement with their reproduction is by being informed and by 'having time' to be *prepared* for either losing a child, or organising life around a child with disabilities before he or she is born.

⁷³ In this particular example of Ema and Claudia, I do not involve the partners of these women because one of the two partners held a rather different position about amniocentesis. For Ema's partner, in contrast to her view, the exam was necessary to provide information that would enable them to interrupt the pregnancy in case of a chromosomal anomaly. For Claudia's partner, amniocentesis was interpreted in similar terms as she did.

But not all women and couples who interpret amniocentesis as a source of information or reassurance, with no necessary link with abortion, articulate their interpretation in the structured way that Ema and Claudia did. Perhaps that structure comes with time and experience. Nevertheless, women who are in the process of having an amniocentesis, and then later on are expecting the results, articulate their interpretations and expectations in a way in which elements of their system of values, and positions towards pregnancy and parenthood, come to the surface. Such is the case of Natalia, the woman whose story opens this chapter. For Natalia and her husband, amniocentesis was interpreted as a tool to help them engage with their pregnancy and, if necessary, be prepared for any eventuality. Abortion, however, was never part of the repertoire of possibilities to which Natalia made reference when discussing whether or not to have an amniocentesis.

Although only Claudia was (once) actually confronted with a positive result, positions towards abortion were rather similar amongst these women, in the sense of not being actively engaged in seeking – or thinking about seeking – an abortion should the amniocentesis results turn out positive. Yet the reasons not to abort were rather different from one woman or couple to the other. For Ema, for instance, aborting a foetus after knowing an amniocentesis positive result appeared a rather disturbing idea:

But really, I think that the issue of selective abortion is very difficult because how can you choose who can live and cannot? ... And also, I have been in contact with, since I was a child, children with disabilities of many types and, believe me, they are lovable children, believe me, they change your life ... Of course these kind of children need very dedicated mothers ... it is not about people being unable. If someone is unable or disabled for doing something we should enable him or her, wouldn't you say?

For Natalia and her husband, the child they were expecting was seen as a miracle. Amniocentesis for them was interpreted as providing information that could be useful for knowing how their baby was, and abortion was not one of their options. Finally, for Claudia and Javier, abortion would have signified the prevention of them mothering/parenting, loving, and caring for their child. For such couples, amniocentesis played a central role in

the realisation of the possibility of caring for and loving their child, since it allowed them to follow their child's progress, and if necessary give meaning to their child's death.

Possibilities and responsibilities

*So doctor [addressed to me, the researcher], is there something they can do to cure the baby?
(Iván, Patricia's husband, 32 years, economist)*

Press & Browner (1997) point out that some women and couples undergo amniocentesis because they 'mistakenly assumed that any problem could be corrected' (Press & Browner 1997: 985). That is the case of Iván and Patricia, who used amniocentesis but were not aware that chromosomal variations are as yet unchangeable; although they were not the only ones, for Eliana and Carlos from the first group, when faced at a certain point with medical uncertainty, also hoped for the possibility of a cure for their baby. In both, and many other, cases I pulled out a photocopy of a negative amniocentesis result for a male foetus to show them, and tried inexpertly to explain to them what is a trisomy or a monosomy⁷⁴. I do not think that my explanation about chromosomes (as much as I tried to make it comprehensible) made much sense for any of them. This was not necessarily because the couples and women were simply unable to understand the technicalities of the chromosomes, as many specialists and fellows think is the case; nor was it necessarily because my lay explanation was confusing. It was, rather, that the matter on which women and couples sought clarity was simple: *is there a cure or not?* If there was something *wrong*, it should be *fixed*. The issue of what chromosomes, trisomies, and mosomies are was not really the point for these families.

The Doctor [Dr Torres] said that it probably was a girl with Down syndrome or with Turner. What is a trisomy? ... And after they have found

⁷⁴ Monosomy is the condition of having one less chromosome instead of two, in a given pair (c.f. Merriam-Webster online dictionary).

out, can they do something to cure her? (Iván, Patricia's husband, 32 years, economist)

When using amniocentesis in this way, the hope for possibilities and medical compliance go hand in hand. Women and couples opt for amniocentesis as part of the inertia of medical encounters in the process of a diagnosis, as shown in Chapter 5. Although there are profound similarities with families such as Eliana and Carlos, who opted for amniocentesis after a morphological variation was confirmed by specialists, families like Patricia and Iván undertake amniocentesis in the hope that the more information about the foetus' condition there is, the more possibilities there are for the betterment of the future child. Therefore, when Iván and Patricia were informed that chromosomal variations do not have a 'medical solution', and that they should decide if they wanted to abort their foetus with monosomy X (Turner syndrome), they were shattered. Not only were they devastated about the condition of the foetus, but also about the fact that they had not been told that whatever the specialists were suspecting (in this case a particular chromosomal variation) had no cure:

They say there is nothing they can do. They should have told us this before, so we were prepared what to expect, so we knew this has no cure. We were hoping that they [the specialists] could do something about the baby, you know? Something whilst she [the baby] is still in Patricia's belly ... but not, there isn't anything to do ... Patricia does not want to abort, she says that it is not right to kill our baby (Iván 32 years, Patricia's husband).

Patricia and Iván, as with Claudia and Javier some years previously, chose not to abort the foetus. In this case, because they did not want '*to kill our baby*', the first baby of a recently wedded young couple who saw in parenthood the next step for fully becoming a family. But amniocentesis failed to provide what was expected of it: to bring the information that would help provide treatment for the child's condition, as the above quotation shows.

A similar case of medical compliance is also demonstrated well by women and couples who have an amniocentesis after the woman tests positive for toxoplasmosis. Whilst

for these women amniocentesis is felt more as a responsible move towards their child, some still hope for medical solutions if the foetus also tests positive for the infection.

It is worth mentioning that amniocentesis for producing a karyotype is different from amniocentesis for ruling out toxoplasmosis. When performed as a test for toxoplasmosis, not only is the rationale for amniocentesis different, but the procedure with the amniotic liquid is also dramatically different⁷⁵. However, women and couples are not always aware of the difference in procedure, and sometimes they misinterpret a negative result for toxoplasmosis as a negative result for chromosomal variations. Such is the case of Paula, who misinterpreted a negative result for foetal toxoplasmosis with a negative result for Down syndrome:

I'm so happy that my baby is alright. I tested positive twice for toxoplasmosis, so the doctor said I must have an amniocentesis to know if the baby has got it as well. I am so afraid of needles, but I thought: *'well my baby first'*. I knew, deep in my heart, that he was alright, but yet I was very very worried, I prayed to God every night: *'please God, please, give me a healthy child'*. You know? I checked on the Internet about this amniocentesis thing and I found out all the things that my baby could have had. But now I'm just so happy that he is alright and he has not toxoplasmosis or that Down disease (Paula, 35 years, accountant).

The interpretation that Paula had about the information amniocentesis was providing does not match the actual function that amniocentesis had in her case. Regardless of her fear of needles, she underwent amniocentesis in the hope that the baby did not have the infection. In the process of waiting for the results she learnt, via the Internet, that amniocentesis also tests for Down syndrome. However, the information she received from the Internet, in the absence of a fluid conversation with her gynaecologist at the moment of presenting amniocentesis, and later when informing her of the results, failed to make

⁷⁵ In the case of testing for toxoplasmosis, no chromosomal count is conducted. In the words of bacteriologist Alma Romero, specialised in cytogenetics: 'When we do amniocentesis for toxoplasmosis we only need the cells to grow a bit and then we test them specifically for the infection. No karyotype is performed there unless the patient or the Doctor asks for that. If they do not tell us, and we use all the amniotic fluid for toxoplasmosis, we cannot do any karyotyping later' (Alma Romero, Genetics Lab A. Interview 2007).

explicit to her the difference between having an amniocentesis for karyotype and having one for toxoplasmosis.

What is also interesting in this example is that for Paula, amniocentesis was something that she owed to her baby; she would overcome fear and anguish in search of the best care her baby could have:

I do whatever it takes for my baby (*por mi bebé hago lo que sea*). Whatever I can do for my baby to be alright (Paula, 35 years, accountant).

From this explanation of Paula's motivation for undergoing amniocentesis, the idea is clear that the information provided by the exam will, eventually, be of benefit to her child. In the case of Patricia and Iván, amniocentesis was interpreted as a source of further information for diagnosis and treatment, whilst for Paula, amniocentesis was interpreted as a means for acting as a responsible mother, who will do whatever is in her reach to secure the health and well-being of her child.

Having come to this point I must say that it would be misleading to assert that all women and couples who are offered amniocentesis opt for having one. As mentioned previously, women and couples provide a myriad of explanations for why they prefer not to have an amniocentesis, dependant on the different interpretations they may have about the purpose and consequences of the exam. In what follows I address the different interpretations of amniocentesis that served as motivations for not having one. However, before going any further, I must clarify that out of the 22 women I encountered and interviewed, only 4 opted out of amniocentesis, and one decided not to undergo a second amniocentesis after the results of the first one turned out to be inconclusive.

To analyse the negativity some feel about amniocentesis and its perceived possibilities is relevant, for it provides a wider understanding of the kind of ideal families to which women and couples aspire. Some scholars (Rapp 1997, 2000; Hunt et al. 2005; Ahmed et al. 2006) argue that within the context of what the test entails and the information it

provides, the most salient motives for declining the possibility of undergoing an amniocentesis is the 0.5-1% risk of miscarriage. Women who do not consider themselves 'at risk' will tend to decline amniocentesis because they consider it undesirable to jeopardise the life of what they believe is a healthy baby. But further, many other women decline amniocentesis because they reject the very idea of abortion (c.f. Ahmed et al. 2006). Contrary to general belief, it is not only moral arguments, sometimes presented in religious terms, which are employed when referring to a rejection of abortion. Ethical arguments dealing with questions such as 'who decides which life is worth living?' or what counts as a disability, are recurrent ones used for declining both the possibility of amniocentesis and selective abortion after knowledge of the tests results⁷⁶.

Child versus information

Doctor [Torres] save your time, stop trying to convince me. I do not need to know that [the foetus' karyotype]. I will love my baby as he is. He is God's gift and that is it (Teresa, 44 years, business administrator/ housewife).

Teresa was a 44 year old pregnant woman. She was one of two women who used a religious stance for expressing her rejection of amniocentesis. Her resolution not to have amniocentesis shows, as well, a level of discomfort in being offered the exam yet again. Dr Torres tried to convince her of the benefits of amniocentesis by highlighting Teresa's risk of having a foetus with Down syndrome, given her age. Teresa, however, found such a risk fairly irrelevant. In a rather matter of fact way she explained:

⁷⁶ For example, Rapp (2000) has pointed out that when studying women's attitudes towards prenatal testing among US natives and immigrants, it is central to take into account ideas of control, experimentation, and history of abuses towards specific population groups, as it is not only beliefs and perceptions about the exam that influence the decision making process. In addition to such things, 'a response to racially differentiated sentiments and histories in relation to medical intervention and experimentation' (2000: 167) mark women's decisions.

Why would I want to know that? What is the point of having that information? We are not going to have an abortion, no matter what, so why would I want to know that about my baby? I will just love the children God gives me as they are.

Teresa defined herself as a practicing catholic, who uses 'the rhythm' as her method of family planning. In her and her husband's view, all children are God's gift and all foetuses are children; hence, aborting a foetus would imply getting rid of one's child.

I just do not find abortion as a credible and good solution. I cannot agree to kill a baby. In all cases one can do something for that child, and if not, adoption is always a possibility.

The link between amniocentesis and selective abortion was crystal clear for Teresa and her husband. In fact, that link was what defined amniocentesis for her. The issue of *knowing* the foetus' chromosomal status in order to be prepared was not part of Teresa's understanding of the function or relevance of amniocentesis. In short, she saw the offer of amniocentesis as irrelevant, because on the one hand it points to abortion, and on the other hand, other functions attached to amniocentesis – such as being prepared for the arrival of a child with disabilities – were not seen as necessary. She felt she could prepare for her child without the information provided by amniocentesis. Given her understanding of and meanings attached to amniocentesis, Teresa was uncomfortable with the constant offers she had for it:

I refrain from that exam [amniocentesis] because it won't change anything, because my baby will be born anyways, and because I will love him no matter what ... This is my child and God gave him to me ... I wouldn't not have it. I would never not have him [the baby].

Teresa would not abort her baby; therefore she would not have an amniocentesis. That much is clear. However, what struck me about Teresa's account was her exasperation at amniocentesis being offered again and again, and for having to explain yet again why she did not want the exam, and why she would not have an abortion should her baby have a chromosomal variation. The fact that she was exasperated shows that she had to explain, almost to the degree of apologising, why she did not want to use the *promising* and *beneficial* technology that amniocentesis is portrayed to be.

Other women also belong to this group *child versus information*, although they did not frame their rejection of amniocentesis in religious terms. Such is the case of Carolina, a 35 year old woman working in advertising. She was the first person I interviewed during my fieldwork. I met Carolina on a February afternoon when I went to have a coffee with Andrea, a school friend of mine. I was supposed to pick up Andrea in her office, but she was extremely busy when I arrived so I was asked to come into her office and wait until she was finished. Andrea had told some of her colleagues that she was going to have a coffee with me, an anthropologist friend doing a PhD in the Netherlands about something related with abortion. I might have been an interesting distraction for this team of artists and publicists working with Andrea, for while I was waiting Carolina approached me and we started chatting. She asked me about my study and I explained: 'I'm studying an antenatal testing technology called amniocentesis, I want to see in what way (if any) amniocentesis is related with abortion de-penalisation and abortion practice'. When I finished my sentence, I expected the usual look of bafflement, accompanied by the empty 'that sounds interesting' which generally ends the conversation. But to my surprise, Carolina said:

Yes, I know that exam; when I was pregnant my doctor talked to me about it. She said that this exam was a very good way for knowing if the foetus had Down syndrome or other problems related to the chromosomes. She explained all about it, but when she told me that the exam had a risk of producing a miscarriage I made up my mind and decided not to have an amniocentesis.

Carolina had been presented with the possibility of amniocentesis just because it was available, not because her gynaecologist suspected or had found any morphological variations in the foetus. Carolina's account for amniocentesis was, as with Ema's, retrospective. She had a one and a half year old son, and she felt she loved her baby from the moment she knew she was pregnant:

This has always been my baby, I looked for him and I wanted him. From the moment I knew I was pregnant I felt a bond with my child, I wouldn't do anything that could harm him.

For Carolina, amniocentesis meant to jeopardise a pregnancy that she had planned and wanted. The perceived value of the information that amniocentesis would provide was not worth the trade off, or the endangering of her pregnancy.

So as soon as I heard from my gynaecologist that I could have a miscarriage I made up my mind and did not even think twice. I was not going to risk my baby just for knowing if he had Down syndrome or any other issue with the chromosomes.

In addition, the possibility for knowing foetal chromosomal information did not seem useful for Carolina. The idea of aborting her baby due to his or her chromosomal status was not part of her repertoire of possibilities. That is, the continuation of her pregnancy was never in doubt:

When my gynaecologist explained the amniocentesis to me, she at one point said, your decision basically depends on what would you do if your baby has any problem, Down syndrome or another problem. So then I understood the value that this exam may have for some women. I mean, if you are inclined to have an abortion if the baby has a condition or a disease, well, the amniocentesis can be important, or usable, or good, I don't know. But for me that was not the case. See, I thought, well if my baby has Down syndrome or any other thing what will I do? Nothing! (*pues nada!*) I am not

going to give up my baby because of that. It was not like I was pregnant for 15 days; I was pregnant for almost 15 weeks, so not, I was neither going to abort my baby nor was I going to risk him just for knowing.

Furthermore, for Carolina the issue of being prepared for a child with disabilities was also not such an attractive feature of amniocentesis:

Yes, there are people who have the amniocentesis because they want to know and get ready, but again, it would have been to jeopardise my baby. Besides, I really don't think you can ever be prepared for what your children will be ... for that you need to have them and get used to them.

Then, the combination of the risk of miscarriage and the possibility of aborting a foetus with a chromosomal variation were two elements that did not combine very well for Carolina, for two, not necessarily unrelated, reasons. On the one hand, as she emphatically expressed, she was not willing to jeopardise her pregnancy, and thus the risk carried by amniocentesis seemed disproportionate to the value attached to the information provided by the exam. But furthermore, this was combined with the fact that Carolina finds selective abortion a disturbing practice. That stance was also related to a deeper rationale informed by a particular understanding of people with disabilities that does not depict them as inherently sorrowful and burdensome:

I mean I agree with abortion. I'm happy that now women can have an abortion in a safe way. Imagine you being raped or something, or that the mother is very sick ... or whatever, I mean if someone wants to have an abortion, well, that is their problem and their decision. But when I think of the possibility of aborting my own baby, and more because he has something, well I just cannot even imagine. People say that it is so difficult to have a child with disabilities, and I'm not saying that is not true. But why would you abort them? What is the big deal of having a baby like that [with disabilities]? But also, we, my husband and I, we have the means for taking care of a child like that. We could afford the expenses in education and the health costs. But that is not only a matter of money, but a matter of disposition. When I was a student at the University I worked with children

with disabilities, with real disabilities and their families were very poor, but they are so lovable that they bring love and joy to their families. If poor people could love and care for their children, why couldn't we? And as I see it, a child like that teaches you so many things, you realise that there are things much more important than those you focus on, those children are a lesson of life. Then, I really do not see what the problem of having a child with disabilities is; I just do not get it.

This latter point is interesting in terms of the class issue raised. Carolina points out that disability and class is not merely or always a matter of money, as children with disabilities may imply a bigger economical effort for parents, but also a matter of willingness and commitment of bringing up a child with disabilities

Carolina, unlike 44 year old Teresa, did not recall having been asked why she refused amniocentesis. Perhaps the fact that she was not pigeonholed into any clinical group may explain why she did not have to battle with explanations for why she did not want to know the chromosomal status of her foetus.

I found one other woman who shared a similar position with Carolina; once again, however, this was delivered though a retrospective account of the encounter with amniocentesis. Camila, a young professional and mother of two, was presented with the possibility of amniocentesis, only because the test is available. There was no suspicion or ultrasound information to suggest the possibility of a chromosomal variation of her foetus. Like Carolina, Camila and her husband decided not to undergo and amniocentesis, basically because of the risk of miscarriage it carries, but also for the functions they attached to the exam and its results:

Well, we did not think about it too much. The decision was easy to make. I mean, we thought that we were not going to abort this baby if it was not alright. Then, if we did not consider abortion, it made not much sense to risk the baby just for knowing information, you know? I don't say I do not see the importance of knowing how your baby is, but the risk was just too high. The issue of knowing for being prepared did not make much sense to us either. I mean, you will anyways have to face it. So we thought, *we better have a good pregnancy and hope for the best* (Camila, 28 years, architect).

In addition to her perception of the trade off between the value and usefulness of the information offered by amniocentesis and the risks the exam carries, Camila was categorical about her stance towards selective abortion based on the foetus' chromosomal or morphological status:

I do not agree with abortion in general, but the case of aborting your baby because he or she is not perfect is simply outrageous. It is as outrageous as a child getting rid of his or her parents because they do not fit what she or he would expect of parents.

Both Camila and Carolina said that if they were offered an amniocentesis again they would, again, decline; again based on the risk of miscarriage.

I also encountered Isabel, a 42 year old school teacher, who, although she was very clear about not looking for an abortion, expressed her views on amniocentesis in a much less articulated way. For her, amniocentesis was just another medical exam, something that would provide her with more information about her future child. However, she declined the offer of a second amniocentesis after the results of the first one turned out to be inconclusive.

When I met Isabel, she expressed the view that the information provided by amniocentesis was not a window for choosing whether or not to bring this pregnancy to term, but rather was to provide a response to her husband's pressure to know how the baby was:

The doctor said that the baby could have Down Syndrome. I am not particularly inclined to have it [amniocentesis], you know, because of the risk of losing the baby [having a miscarriage] but my husband is very interested in knowing. I mean, I am doing this [the amniocentesis] because he has been very persistent on it. If it were for me, I would just leave things in peace and not risk my baby.

Although Isabel was looking forward to receiving the information provided by amniocentesis, she also seemed somewhat uninterested. Her main concern was that her husband was not looking forward to having the future child:

Well, I'm here; as I told you it seems that the baby has something wrong. My husband is not very happy about this child, and with the possibility of it having something wrong even less ... the pregnancy was a complete surprise to both of us, but I was taught that if things happened different than expected one does not sit and think about why and how things happened in such a way, but one starts moving on and assumes the consequences of one's acts. This pregnancy is like that, in spite of the situation of the baby [making reference to the possible Down syndrome]. I told him [her husband] that if he did not want any children he should have thought of that before [having unprotected sex], you understand me?

Despite amniocentesis' offer of useful information, it does not always deliver that which it is supposed to and promises. After the amniocentesis results arrived I met Isabel. The results were inconclusive:

No salió nada, dicen que creció muy poco, nothing turned out [negative results—no visible chromosopathies], they say that almost nothing grew [from the sample of amniotic fluid]. But they say [in the report] that I should have a second amniocentesis or a cordocentesis for being sure ... No, I'm done with this. Furthermore, who tells me that this time it will work? I'm going through a difficult [family] situation and all this is making things more confusing ... My husband just told me that he has a girlfriend, no wonder why he was so unhappy with this pregnancy, and I'm expecting a child that I do not know how it will turn out to be (*que no sé como va a salir*). But Mafe [me, the researcher], I don't care, you know? Now this child is being my company, he is with me all the time and he is my support and my strength. I talk to him all the time. I already love him so much. I have named him Manuel José ...

In Isabel's accounts, as well as in the many conversations we had, the issue of abortion was never expressed as such. Her position towards life – *'if things happened different*

than expected one does not sit and think about why and how things happened in such a way, but one starts moving on and assumes the consequences of one's acts' – speaks meaningfully about her position towards abortion; but moreover, about her understanding of pregnancy, parenthood, and antenatal life. With such a mindset, aborting an unexpected child, or a child with disabilities for that matter, would signify walking out on the responsibilities she took on when embarking on an active sexual life. For Isabel, motherhood and pregnancy are experienced as a matter that has no point of return. In her set of moral and ethical values one does not choose not to have a child, once it has been conceived. She had the amniocentesis once because she, or rather her husband, wanted to know how the baby was, chromosomal wise. But Isabel was not willing to undergo either another amniocentesis or a cordocentesis, the latter of which carries a higher risk of producing a miscarriage. The first amniocentesis counted as enough risk being taken with not enough 'back-up'. Her trust in the exam was now too little to undergo another amniocentesis, and her bond with her child was too strong for the information the test could bring (if at all) to have any consequence for her.

Final comments

Through women's and couples' accounts in this chapter I have shown that amniocentesis brings ideals of *normality* close to hand, at the same time as it brings pregnancy and motherhood to another level. I have also shown that women and couples are not submerged within a technological determinism that supposes all pregnant women and couples react equally, both to the possibility of undergoing an amniocentesis and to the possibility of an abortion. Functions attached to and interpretations of amniocentesis are many. Some connect the availability of amniocentesis and the possibility of aborting foetuses 'incompatible with life' with the possibility to choose (or decide) who is good enough to enter the human community. Some connect it with the possibility of adapting pregnancy and offspring according to a life plan. Hence, for many the question is not so much how difficult or burdensome it is to raise a child different from the average (though it undoubtedly is); the question relates more to what one has to give up in order to fulfil family, career, and life plans simultaneously and successfully. Such decisions were shown to

respond to motivations regarding understandings of pregnancy, parenthood, and antenatal life, and family and life plans.

For some others, depending on their life plans and moral and ethical values, and the way in which each of these is conceived and experienced by women and their partners, amniocentesis may have different functions and points of relevance. Some rely on amniocentesis as a source of information that will enable them to be prepared for the arrival of a child with disabilities. Amniocentesis is then perceived as a source of control for families and individuals, for it presents the opportunity to get ready, to be prepared for living with a child different from the average. Women and couples refer to logistical and emotional preparation, implying by this that there is an emotional shock produced by having a child with disabilities, and that it is possible to anticipate and get ready for life's difficulties and hardships. Both lines of thought deserve attention.

The idea of the *need for preparation* relates to the understanding that children with disabilities are abnormal, and therefore bring extra difficulties to families and individuals. The idea of the *possibility to be prepared* evidences a level of faith in the capability and possibility of controlling the future, that technologies such as amniocentesis appear to provide. Information referring to the health status of the foetus implies for some women and couples *to be prepared*; not necessarily, however, for having a child with disabilities, but for having the opportunity for parenting and loving a baby that will die in utero. For yet other women and couples, amniocentesis is seen as a source of further information that will help to determine a course of treatment for curing or bettering the future child.

With these different perspectives on amniocentesis given by users of it, it is possible to conclude that amniocentesis reinforces stigmatising understandings and attitudes towards people with disabilities, whilst at the same time it enables families to control their relationship with such individuals, whether by selectively aborting them or by preparing for their arrival. But amniocentesis serves also for helping and enabling prospective parents to be prepared for the imminent death of their child, or it allows prospective parents to be responsible and follow a medical procedure that will somehow ensure the well-being of their child.

Conversely, through the voices of women and couples who opted out of amniocentesis, we hear that they did so because this particular antenatal life had a value and a potential that was independent of chromosomal *normalcy*, or because they did not view a child with disabilities as disrupting their life plans in a way they could not countenance. The rejection of amniocentesis and of selective abortion was not necessarily presented in religious terms (although that was sometimes the case), but also as an ethical conviction toward pregnancy and family life. The refusal of amniocentesis also enables women and couples to produce and pursue a family that is ideal, though in a different sense. By declining the offer of amniocentesis, women and couples are enabled to position themselves in relation to their moral and ethical standards regarding pregnancy, parenthood, and antenatal life. By opting out of knowing particular pieces of information about their future child, prospective parents pursue the realisation of what they consider a desirable family: one that does not choose its members, but one that appreciates each of them as equal regardless of their individual differences.

In sum, in this chapter I have shown the different moral and ethical reasoning that may move women and couples to decide whether or not opt for an amniocentesis. This sheds light on the different perceptions of pregnancy, parenthood, and antenatal life that amniocentesis makes visible and that it enables. Furthermore, such different positions towards pregnancy, parenthood, and reproduction are deeply interwoven with prospective parents' attitudes towards antenatal life, family life, life plans, and people with disabilities.

Finally, through the narratives of women and couples I was able to present the different functions and meanings attached to amniocentesis, that make evident the variety of interpretations and possibilities that a given technology may have, in a given cultural and historical context.