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

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## Introduction

This is a study of discrimination. It started out as an attempt to elucidate apparent incongruities in Colombia between medical possibilities such as genetic antenatal testing and the legal system. However, this subject did not stay put. During the course of the study the legal framework of abortion changed – it was de-penalised – as did the focus of this study, the research question, as well as my stance on antenatal genetic testing and selective abortion. Thus it became a study of the relationship between abortion de-penalisation under the conditions of foetal morphological or chromosomal variations, and the availability, use, functions, and meanings attached to amniocentesis in Colombia, with regard to the social imaginary of desirable citizens.

### Accounting for this research

I came to know about amniocentesis a few years ago when a close friend of mine and his wife became pregnant. Given that both were over 40 years of age, the Ob-Gyn who took charge of the pregnancy recommended an amniocentesis. Both agreed on having the exam, as they were aware of the *risks* involved in having a child at their age. The possibility of aborting the foetus '*in case there is a trisomy*'<sup>1</sup> was not altogether dismissed by my friend. At the time I told him that I did not know that it was possible to abort in Colombia. '*It is not, but that is another matter*', he answered.

Two years later, when I was already living in the Netherlands and was thinking of possible PhD research topics, my sister became pregnant with her second child. One day when we were talking over the phone she told me that her Ob-Gyn had suggested that she – a 28 year old woman – undertake an amniocentesis. I asked her why and she said, '*Well just*

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<sup>1</sup> Following the online dictionary Medicine Net.com, a trisomy is 'the condition of having three copies of a given chromosome' instead of two. <http://www.medterms.com/script/main/art.asp?articlekey=38317>

*to be sure the baby is alright'. 'What are you going to do?' was my next question, and without a second thought she answered, 'Well, I am not having that exam, they will put a needle in my belly... But also, we were thinking, no matter how this baby is we will have it. I mean, we wouldn't have an abortion, so what is the point of having that exam?'*

What moved my friends and my sister either to undertake amniocentesis or to reject it respectively was its relation to abortion. The fact that abortion was fully penalised in Colombia made me wonder why a state that allowed women and couples to have access to such an exam opened no legal possibilities for action in case the amniocentesis showed an undesirable result. Why were they not allowed to have a legal abortion?

To me, at that time, both the exam and selective abortion made perfect sense. Today, after conducting this research, I must say I find both practices rather problematic.

At the time when I was writing the research proposal, in May 2005, the lawyer Mónica Roa presented a law suit before the Constitutional Court in Colombia. She sued the Penal Code's article 122 that penalised abortion. For Roa, to prohibit abortion in cases of rape, when the pregnancy endangered the woman's health, or when the foetus suffered conditions that made it 'incompatible with extra-uterine life' (Roa 2005a: 16), contravened a number of human and constitutional rights. Roa's point about the need for granting the abortion of fetuses with a diagnosed condition made evident for me, once again, the intertwinement between antenatal testing and abortion.

My core question always revolved around the idea that through the relationship between the legal status of abortion and the availability of amniocentesis for assessing chromosomal or genetic conditions, Colombia was somehow seeking to achieve a 'desirable nation' in terms of the composition of its citizenry. By the time of Roa's first lawsuit I wanted to study the relationship between the political, legal, and social spheres in (re)shaping what is taken to be a 'desirable nation': whether it is understood in terms of the 'quality' of the citizens (through de-penalising abortion), or in moral/religious terms (i.e. to keep abortion penalised, for such a practice was conceptualised as unacceptable in moral-Catholic terms).

By May 2006, after a series of lawsuits and a heated debate in which the Catholic Church and the pro-life movement exerted strong opposition, Sentence C-355/06 de-penalised abortion under the three conditions mentioned by Roa. In this new legal panorama, it made little sense for me to wonder about which position the country would take. With abortion made flexible, what I then found worth studying became: *How have the different renderings that the foetus and its genetic status have acquired over time enabled new understandings of reproduction in Colombian society (the family, the medical setting, and parliament), so that they could be reconciled with changes to abortion law?* What I especially wanted to understand were the new conceptualisations of the foetus, enabled by antenatal testing technologies, that made it legally acceptable to abort what until recently was understood as a human being. I took as a starting point the notion that a new definition and understanding of the foetus must have been made possible, and that this led to the possibility of aborting foetuses with particular conditions.

With such questions on mind I started this research and conducted a one year fieldwork. However, during the last months of fieldwork and whilst writing this thesis I came to realise that the new conceptualisations of the foetus, although relevant, played a less central a role in abortion de-penalisation, the practice of selective abortion, and in the use of amniocentesis for determining chromosomal status, than that of three centuries in which the ideal of a Colombian physical and social body took shape. This is an ideal rooted in Enlightenment and Modernity thought, that lies in the very foundation of the articulation of Colombia as a Republic and as a Nation. An ideal that promoted the discrimination against particular groups of people, amongst which people with physical, but most importantly intellectual differences, were included. Thus, the research question became: *How has the use and availability of antenatal technologies, of the type of amniocentesis, in combination and interaction with the practice and de-penalisation of selective abortion, helped elucidate a Colombian social imaginary of desirable citizens?*

Amniocentesis and genetic studies

Two matters need to be addressed in order to apprehend the dimensions of the research core. First is a definition of what amniocentesis is today, and second, a problematisation of genetic technologies and their relation to past attempts to ameliorate the human race (cf. Kevles 1995; Paul 1998; Gupta 2000).

*'The fishing expedition'*<sup>2</sup>

Since the discovery of the DNA double helix in the sixties, studies trying to disentangle, understand, isolate, and finally manipulate the genetic code have been increasing in number and importance (Gupta 2000). Such technological advancements have made it possible to carry out, among many other things, foetal genetic testing for diagnosing chromosomal and genetic conditions (Rapp 1993). One such test is amniocentesis, which today assesses foetal genetic and chromosomal status in order to exclude the possibility of conditions such as Down Syndrome 'and other chromosome disorders ranging from severe and deadly, like trisomy 13, to the ambiguous, like the sex chromosome anomalies, Turner's or Klinefelter's syndromes' (Rapp 1997: 63), as well as a growing number of genetic disorders (c.f. Singer et al. 1999). Broadly speaking, this test is mostly offered to women for whom foetal genetic conditions are suspected, whether because of early ultrasound detection of alterations in the foetus' morphology, family history, or because of the mother's advanced age (depending on how 'advanced' is defined). Amniocentesis is preferably practiced between the 15<sup>th</sup> and 18<sup>th</sup> week of gestation, however 'researchers aim to separate the very small number of foetal cells circulating in maternal blood within days or weeks of the onset of pregnancy, so that antenatal diagnosis can be made even earlier' (Rapp 2000: 30). If the likelihood of a variation is established, pregnant women and couples are offered genetic counselling, and abortion becomes one of the possibilities if they decide not to bring that specific pregnancy to term.

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<sup>2</sup> Rapp (2000: 28)

The amniocentesis exam is performed by introducing a 9cm hollow needle into the uterine cavity of a pregnant woman, and 1mm of amniotic fluid per week of pregnancy is extracted. In this liquid are floating foetal cells, which are then grown in a genetics laboratory until they reach metaphase, which is the moment in which chromosomes may be counted, and thus a Karyotype<sup>3</sup> established (Dr Santos, personal communication, 2007). Other usages of amniocentesis, which will be addressed later, are for ruling out foetal infections, and for reducing an excess of amniotic fluid (Dr Rincón, personal communication, 2007). Nevertheless, the most salient usage of amniocentesis is to provide foetal genetic information that can be used for making reproductive decisions. Such a close relationship with abortion has made the test a contested practice, as it transforms the abstract question of ‘what counts as a desirable human being’, into a real practical one defined in terms of genetic make-up (c.f. Rapp 2000). In this sense, it is not amniocentesis itself that has faced severe and long lasting critique, but the larger science it is related to, namely, human genetics.

#### *Defining and choosing ‘better’*

Long before this well known and widespread term coloured by hope in a healthier future was coined, human genetics was nothing but Galton’s eugenics. In 1883 Francis Galton coined the term eugenics, derived from the Greek word “eugenes” that means “of good birth”. Eugenics ‘emerged as an extension of the science of heredity and claimed to apply genetic principles to the improvement of “mankind”’ (Gupta 2000: 476). As a social movement, eugenics was based on the premise that society should guarantee the constant improvement of its human stock. This was done ‘by encouraging “fit” individuals and groups to reproduce themselves and, perhaps more important, by discouraging or preventing the “unfit” from continuing their unfitness to future generations’ (Stepan 1991: 1-2). Due to large scale abuses brought upon entire populations, the horrors of the Holocaust being one of the most visible cases, eugenics became an embarrassment within scientific and social circles, especially in Great Britain and the United States (Kevles 1995: 251).

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<sup>3</sup> A karyotype is the ‘chromosomal characteristics of a cell, also the chromosomes themselves or a representation of them’. Merriam Webster Medical Dictionary. Online source at: <http://www.merriam-webster.com>

Stepping very much aside from human beings and human genetic manipulation, studies of heredity began to focus on other living beings (animals and plants) until the discovery of the DNA double helix, when research into human genetics bloomed. The intentions behind studying and manipulating human genes were framed as essentially amending for, or at least avoiding the repetition of, past (unforgivable) mistakes; so human genetics developed within medical research in search for cures to disabilities and diseases (Kevles 1995; Gupta 2000). This quest led eventually to the replacement of the term eugenics with the term *human genetics*, believed to be neutral by its first users at Galton's laboratory at University College London (Kevles 1995: 252). The combination of advancements in genetic knowledge, the discovery of trisomy-21 in 1959 as related to Down Syndrome, and a brand new name for the field which imprinted hope in the human genetics pursuit, smoothed the path for further research. In such a scenario, the routinisation of amniocentesis came along (Kevles 1995; Rapp 2000). Further, clinical trials amongst large numbers of pregnant women proved amniocentesis' vast potential for providing quite a complete index of foetal genetic status. This made the exam popular practice and a source of authoritative knowledge in Europe and the US, and from there it travelled to other locations.

Yet despite the value of research into human genetics, and its subsequent "beneficent" applications, questions regarding its potential for provoking another wave of massive selection by societies of *perfect* individuals have been posed (and somewhat addressed). Kevles (1995) for instance stresses that the socio-political context of today's human genetics diminishes the 'the likelihood that the revolution in human molecular genetics will be turned to eugenic ends' (Kevles 1995: xii). Nevertheless, he goes on to point out that '[t]he ability to acquire genetic information has created the capacity for what has been called a kind of "homemade eugenics" – individual families deciding on the kind of children they will bear' (Kevles 1995: xii). In other words, there might not be a state mandate for population control, but there are individual and social tendencies to do so.

Antenatal testing is believed to be strongly linked to eugenics because, as Mateu points out (2002: 236), '[i]n most cases, the motivation for genetic testing or interest in genetic information [is] related to reproductive decisions'. In this sense, one of the expected responses to positive antenatal testing is abortion, and one could say that this is a form of

choosing offspring in terms of genetic quality. In this respect, Rapp (2000: 37) remarks that many geneticists in the United States assume that by giving the option to terminate *affected* pregnancies, a test such as amniocentesis in a way implies ““positive eugenics” factors (...), for screening promotes the reproduction of healthy offspring; but there are no “negative eugenics” factors, for no central powers are limiting who may or may not reproduce’. Similarly, Elger & Harding (2003: 327) distinguish between three types of eugenics: ““Individual eugenics” in the form of genetic counselling, “social eugenics” meaning social pressures through the idea of “responsible parenthood” ... [and] “liberal eugenics” ... [which] denotes eugenics that is not mandated by the State on authoritarian grounds, but freely practiced by couples on the basis of their individualistic preferences’.

In effect, women and couples are making decisions, and so marking standards, for what counts as a proper human being good enough to be part of the human race (Rapp 2000: 3). In this sense, amniocentesis is far from merely an individual matter. Investigations of antenatal testing should provide a solid ground for understanding individual practices like reproduction, but also need to go beyond what happens at the level of individuals and also address how socio-cultural and historical realities change over time in relation to such practices.

Such research must acknowledge that society is not merely a passive recipient of technology. Consumers and performers of antenatal technologies such as amniocentesis also shape its use, status, and function. This study will show how this is so.

*The regrettable importance of Galton<sup>4</sup>. Society and genetic information: becoming public.*

As discussed previously, the fact that high numbers of women undertake antenatal testing indicates that amniocentesis cannot be understood nor researched as a mere individual event, but needs to be approached as a social phenomenon. Such a claim relies not only on the fact that pregnancy is a social event by definition, nor because antenatal testing provides prospective parents with foetal genetic information upon which they can

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<sup>4</sup> Rabinow (1993: 64).

base their reproductive decisions. It is also because such a practice speaks eloquently of socio-cultural values that (due to the availability of genetic testing) come to be more salient, while others become relative and contested: the value of antenatal life, the definition of the foetus and health, and the value of people with disabilities. In order to comprehend why many social scientists (c.f. Rabinow 1993; Paul 1998; Gupta 2000; Brodwin 2005) and geneticists (c.f. Csaba & Papp 2003; RNAAS 2004) argue that the availability of genetic knowledge, whether pre-implantation, foetal, or postnatal, has a major impact on societies, one needs to step back and understand the origins of genetic counselling, since it is through such a discipline that prospective parents are informed about their foetus' condition and about their reproductive possibilities.

In 1947, Sheldon Reed coined the term 'genetic counselling' to define the genetic advisory services provided at the Dight Institute for Human Genetics at the University of Minnesota (Kevles 1995; Paul 1998). The discipline was established as part of the effort to use genetics for medical purposes whilst avoiding the negative connotation of eugenics. Kevles (1995: 253) remarks that people sought genetic counselling principally because they suspected the possibility of being carriers of a condition that could be passed on to their offspring, or because they had already given birth to a child afflicted with what was thought to be a genetic disorder. Even though Reed envisaged genetic counselling 'as a kind of genetic social work without eugenic connotations' (Reed, quoted in Paul 1998: 133), during the 1950s and 1960s most genetic counsellors understood and practiced genetic counselling as an extension of eugenics. For most genetic counsellors, fetuses different from the average should be aborted and carriers of conditions, disorders, or diseases should not reproduce (Paul 1998: 133-34; c.f. DeMars et al. 1969; Shaw 1974). However, even for Reed, counsellors should not direct counselees in decision making, as reproductive decisions should rest only with the couple (Paul 1998: 134). This is how the practice is conceived today (Rapp 2000).

However, the focus on personal autonomy 'has obscured the fact that individual reproductive decisions do have social consequences and that in a market system the privatisation of such decisions will result in their commoditisation' (Paul 1998: 108). In this respect, Nozick (quoted in Paul 1998: 108-09) refers to a 'genetic supermarket' that allows

prospective parents to 'order' the kind of offspring they want to rear, as the market's power replaces that of the state when it comes to population control. Nonetheless, one must bear in mind that at the level of public policy making, genetic services 'were and are still funded in hopes of reducing the incidence of genetic disease and thus saving the state money' (Paul 1998: 148). Hence, despite the commitment to individual autonomy and the apparent absence of governmental eugenics programs, states are promoting a salient ideal of what constitutes a healthy (and therefore 'desirable') individual for a healthy society, as will be shown in Chapter 4. The medicalisation and pathologisation of a great number of conditions with which pregnant women are confronted, and are pressured by society to abort, are informed by public health officials' and insurance companies' understandings of *unfit*, and therefore *undesirable*, individuals (Gupta 2000: 449). This, I would risk to say, is highly determined by economic factors, in terms of costs and *burdens* of particular conditions. In this sense, not only foetal genetic knowledge, but also postnatal genetic information of newborns, children, adults, and elders, performed either for personal purposes or to entire human groups<sup>5</sup>, have led to new definitions of health and disease, and have helped to refine existing definitions.

As previously highlighted, today's genomic quest has been portrayed as different from the eugenics movement of the late 1800s to mid 1900s, to the extent that states do not mandate "race cleanliness" (c.f. Kevles 1995; Paul 1998; Gupta 2000). But, as Elger & Herding (2003: 328) highlight, reproductive decisions made upon foetal genetic information may involve a move towards the betterment of humankind and so have consequences for societies. Moreover, such an attempt to improve the coming generations is not only informed by individual preferences, but also by social and cultural pressures, as for instance the general depiction of disabled individuals as an economic burden to families and to societies (Paul 1998: 104).

Such a depiction of eugenics corresponds to the US and most of Europe. In Latin America, however, the eugenics movement took quite a different form. As will be shown in Chapter 4, the particular nature of the movement in countries of that region make even more

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<sup>5</sup> Such as the Human Genome Project, and the Human Genetic Diversity Project.

evident as eugenics practices the link between amniocentesis used for determining foetal karyotype and selective abortion.

Besides the history of discrimination against people with disabilities, there is another point that makes it possible to link selective abortion based on foetal chromosomal or genetic status to eugenic goals. For many families, notions of the foetus, pregnancy, and parenthood become equated with ideals of quality of life for both prospective parents and prospective child, so choices are made about what type of offspring families are willing to rear (Csaba & Papp 2003). In this respect, Paul (1998: 167) draws attention to how the recent ideal of *responsible parenthood* has coloured the notion of the 'right to be born', primarily in the US. Such a 'right', which is defended by abortion opponents, is now being qualified by the right to have the chance to achieve a happy and successful life. This new qualification of the 'right to be born' is very problematic in two senses. Firstly, it assumes that individuals who are medically diagnosed as having a disability are inherently unhappy and unsuccessful. Secondly, it places the responsibility of the unhappy and unsuccessful life of the future baby on the parents who decided to bring a foetus different from the average to term. What the defendants of such a thesis fail to underscore, whether in the US, Europe, or Latin America, is that social factors such as education, employment, and discrimination play a central role in what is called a life with 'reduced chances' (Parens & Asch 2003: 40). Medical information regarding genetic disabilities is taking over cultural dispositions, disabling people by using a universalising language and thus obscuring the senses in which disabilities are a social construct; that it is society that stigmatises, reduces life chances, and segregates those who are regarded as *unfit* (c.f. Das & Addlakha 2001).

With regard to ethical concerns about antenatal testing in Europe, in a symposium held in the Netherlands in 2003 on antenatal testing, geneticists pointed out that a considerable number of couples decide before becoming pregnant that they would not rear a child with disabilities. Thus their pregnancies start out as 'tentative pregnancies'. Geneticists in the symposium were concerned with whether or not such pregnancies are ethically defensible (RNAAS 2004: 50). Furthermore, it is believed by some geneticists that the rapid growth of genetic knowledge will inevitably lead to the selection of specific traits and the elimination of others, not only in terms of disorders but also in more general terms, as for

example sex selection. Given this climate, there is growing concern amongst geneticists pertaining to the boundaries that should be drawn for antenatal testing (c.f. Csaba & Papp 2003; RNAAS 2004), and on the need to rule which type of genetic or chromosomal disorders should be regarded as arguments for terminating an *affected* pregnancy (Csaba & Papp 2003).

However, the question then arises as to who should assess how painful, serious, or emotionally burdensome a given disorder is. For the Colombian case, where abortion is now granted to a woman who carries a foetus suffering 'conditions that make life unviable outside the maternal uterus' (Sentencia C-355/06), on what basis can one assess what constitutes incompatibility with extra-uterine life? Or rather, how far can the term 'incompatibility with extra-uterine life' be stretched? Should it, for instance, include the susceptibility for breast cancer, or the existence of a late-onset conditions such as Huntington's disease? Should it take account of scarcity of resources, not only limited social services for children with disabilities, but also for children from poor families? Who can and should assess that: medical professionals, the prospective parents?

Genetics, like all technologies, is not a fixed neutral entity (c.f. Mitchell & Georges 1997). Individuals, given their daily lives, lived experiences, worldviews, and beliefs, attach meaning and value to genetics, while at the same time collective responses to the availability of genetic information are culture bound. Factors that play a part are representations in the media, the public and private discourses used by medical practitioners when referring to genetics, the status that geneticists and genetic knowledge have in a given social group, and the availability of genetic testing to different sectors of society. These are central aspects in determining the prevalence and importance of genetic information and genetic conditions, and therefore their consequences for particular societies. As suggested by Van der Geest (2002: 13) 'what the patient feels is not biologically determined but is situated in a web of socio-cultural and psychological meanings', which make medical phenomena 'the conjunction of social interest and values'. Technologies have no universal effect on users; nor have they a uniform effect on societies (c.f. Casper & Koenig 1996; Mitchell & Georges 1997). They should be regarded as plastic categories since they have different functions,

explanations, connotations, and effects on the societies in which they are deployed (Casper & Koenig 1996).

Although discrimination in genetics discourse appears to be a constant, those who are discriminated against vary from one country and context to another. Dilemmas that confront societies are not reducible to general ethical guidelines which depart from understandings of genetic technologies as neutral, and disregard the socio-cultural context in which such technologies are deployed.

### Problem statement

Within this framework, this study explores how the use and availability of antenatal technologies, of the type of amniocentesis, in combination and interaction with the practice and de-penalisation of selective abortion, help elucidate a Colombian social imaginary of desirable citizens.

The availability of foetal genetic information has enabled multiple and new definitions of the foetus. The first of such makes the foetus an object of research from which valuable information can be retrieved. Alongside the definition of the foetus as a research object appeared an understanding of the foetus as a 'tentative' being, given that results of research could signify that the foetus would be dismissed. At the same time, such information, as well as the categories it produces (i.e. ill, healthy, able, disabled), are inscribed in a tradition of knowledge that has deep roots in the marking of human beings in terms of fitness and intellectual quality. Furthermore, genetic technologies, amongst which is included amniocentesis testing for foetal genetic and chromosomal (ab)normalcy, are producing (and reproducing) an illusion of universal determinants (LeBreton 2004) that overrule cultural explanations of diversity. This provides the grounds for perpetuating ideals and beliefs regarding differences between *fit* and *unfit* individuals, and the archetypical life of both, overstressing what are considered to be the downsides of *unfitness*. Based on such archetypes and moved by an urge for normalcy, individual reproductive decisions are being made based upon positive amniocentesis results. Nevertheless, despite

the fact that they are made on the individual level, reproductive choices do have social implications, and are informed by wider socio-cultural and historical values.

In such a context, my core argument is that, for the Colombian case, the abovementioned definitions of the foetus, legal changes to abortion penal status, the practice of selective abortion, and the will to know one's foetus' karyotype, are interrelated elements that respond to deep rooted definitions of what a desirable citizen, family member, and human being should be. Furthermore, they are clustered today under the umbrella category of 'conditions that make life unviable'. Such roots run across time and space, since they have been discussed for more than one hundred years already, and gain shape and meaning in different geographical and cultural locations. In other words, in Colombia a long history of discrimination, in combination with the availability of antenatal testing technologies, and constitutional changes to secularise the country is what led to abortion de-penalisation. Similarly, the practice of selective abortion and the use of amniocentesis as they are today (and have been for many years already), resonate with a socio-cultural context which has seen years of structural discrimination against specific groups of people. The ways in which practices and social imaginaries are intertwined are visible when one looks at the category of 'conditions that make life unviable', also referred to as 'incompatibilities with life'. I argue that such a category is multiple (Mol 2002), plastic, and ambiguous, referring not only to 'biological life', but also to 'social life' and lifestyles.

Within this framework, I find it important to approach amniocentesis as a social phenomenon and not only as an individual matter. Such a technology provides information upon which decisions regarding a population's composition are made, and at the same time it shapes to a great extent law, family planning, and attitudes towards people with disabilities (c.f. Shakespeare 1998; Rapp 2000). But it is also paramount to see amniocentesis as a vehicle for exploring the category of *normal*. Where is it produced? What and whom does it represent? How and why did it become so visible?

I propose to explore amniocentesis within the wider socio-cultural and historical context of Colombia, departing from the understanding that the functions, uses, categories, and repercussions attached to and produced by a particular technology depend on a given time-space scenario (Latour 2002). This will shed light on how the individual practice of

amniocentesis, and the apparent individual concern of selective abortion, relate, inform, shape, and are shaped by abortion de-penalisation.

### Theoretical considerations

#### *Conceptualising amniocentesis, the practice and de-penalisation of selective abortion, and eugenics*

In order to be able to conceptualise amniocentesis, the practice and de-penalisation of abortion, and eugenics, I have relied on two theoretical concepts that help to understand the connections between them. These theoretical concepts are *social imaginary* (Gaonkar 2002), and *biopower* (Foucault 1976, 1980). Both concepts are useful theoretical and methodological tools.

Social imaginary helps to elucidate the dynamics between the individual and the public spheres, for, as expressed by Gaonkar (2002), it enables an understanding of how old ideas and practices are either strengthened or de-legitimised by new ideas and cultural practices. The social imaginaries, as defined by Gaonkar (2002: 1), are ‘embedded in the habitus of a population or carried in modes of addresses, stories, symbols and the like... they exist by virtue of representation or implicit understanding, even when they acquire immense institutional force’. Gaonkar (2002: 2) also points out that ‘the nation people is a paradigmatic case of modern social imaginary’, to the extent that nation involves a sense and definition of “we”, that links the individual with the collective. Consequently, social imaginaries are ‘more than an immediate practical understanding of how to do particular things – such as how to buy a newspaper, ride a subway, order a drink, wire money, make small talk, or submit a petition. It involves a form of understanding that has a wider grasp of our history and social existence’. In this sense, ‘social imaginaries occupy the fluid middle ground between embodied practices and explicit doctrines’ (Gaonkar 2002: 10-11). In this context, the centrality of the public sphere is evident, given that it is the place in which social imaginaries come into being, are reinforced, or are displaced by new imaginaries, through the interaction of individuals with one another through discursive practices, which are an act of world making (Gaonkar 2002: 16).

Similarly, the concept of biopower helps in understanding the interaction between amniocentesis, (selective) abortion practice and abortion de-penalisation, and structural discrimination which can lead to eugenics. This is particularly so in relation to the conceptualisation of healthy and desirable bodies. For Foucault (1980), in times of the Monarchy the physical body of the King was a political reality, and represented the Kingdom. In times of the Republic there was no King's body, but the idea of the social body as the reality of the Republic appeared in its place. Hence, society needed to take care of its social body, and the previous 'elimination of hostile elements by the *supplice* (public torture and execution) is thus replaced by the method of asepsis – criminology, eugenics, and the quarantining of 'degenerates'' (Foucault 1980: 55). The very bodies of individuals became the locus of power exercised in search of the maintenance and achievement of a healthy social body: 'Now the phenomenon of the social body is the effect not of a consensus but of the materiality of power operating on the very bodies of individuals' (Foucault 1980: 55). Through this practice, reproduction, health, sexuality, and behaviour became a focus for State concern, and measures to discipline the individual body were enacted.

However, in the eighteenth century emerged another sort of power and its associated technology, which 'does not simply do away with the disciplinary technique, because it exists at a different level ... and because it has a different bearing area... this new nondisciplinary power is applied not to man-as-body but to the living-man ... to man-as-species' (Foucault 1976: 242). This new power seeks to regularise populations, and is what Foucault called a "biopolitics" of the human race that searches to control or regularise illnesses (and differences) seen as affecting a population. In Foucault's words, 'what we are dealing with in this new technology of power is not exactly society ... nor it is the individual-as-a-body. It is a new body, a multiple body... Biopolitics deals with the population' (1976: 245). It is in such a context that Foucault (1976: 247) refers to biopower as 'power over the population as such, over men insofar as they are living beings'. In the struggle to regularise the population, medicine as a science and a technology gains in importance, for 'medicine is a power-knowledge that can be applied to both the body and the population' (Foucault 1976: 252).

Yet, power<sup>6</sup> should not be understood as merely the repression, exclusion, or censorship of acts. 'If, on the contrary, power is strong this is because ... it produces effects at the level of desire – and also at the level of knowledge. Far from preventing knowledge, power produces it' (Foucault 1980: 59). Further, the knowledge produced by power becomes a hegemonic truth. Such is the case of medicine, of Human Rights, of criminology – to mention a few examples – which are apparatuses set to differentiate the *normal* from the *abnormal*; the long quest for discipline and normalisation. However, as mentioned before, 'it is medicine which has played the basic role as the common denominator. Its discourse circulated from one instance to the next. It was in the name of medicine both that people came to inspect the layout of houses and, equally, that they classified individuals as insane, criminal, or sick' (Foucault 1980: 62). Such hegemonic definition and classification of individuals continues to date.

The usefulness of these two theoretical concepts lies in the insight they provide into how practices, ideas, and notions shared by a people have commonalities that surpass the individual, whilst leaving room for individual interpretations and variations. Foucault's notion of power does not imply that individuals are unable to make decisions or to disagree. However, as mentioned above, power has an effect at the level of desire and knowledge, and thus it contributes greatly to and shapes understandings of what is good, bad, normal, abnormal, ill, healthy, and so on and so forth. Similarly, Gaonkar's definition of social imaginary helps understanding of how behavioural and ideological ideas are reproduced almost automatically, yet individuals' lived experiences also contribute to either reinforce or de-legitimate a practice, idea, notion, belief, and so on.

### *Boundaries of knowledge*

The two aforementioned theoretical concepts provide a solid ground for approaching the practices of amniocentesis for foetal karyotype, selective abortion and abortion depenalisation, and structural discrimination in the form of eugenics. Further, these concepts

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<sup>6</sup> Power, as a sociological category, has also been widely studied by authors such as Weber, Marx, Aron, and Gramsci, to mention but a few.

will be articulated through the use of three major schools of knowledge: Medical Anthropology, Science and Technology Studies, and Disability Studies. I also make use of some of the theoretical contributions of Law and Anthropology, especially for understanding penal changes in relation to the practice of abortion.

Given this affiliation with different disciplines, I would say that this study is an interdisciplinary one. Anthropology's conception of the social and the individual serves as the starting point for Medical Anthropology, to the extent that the latter understands the role of medicine (whether biomedicine or otherwise) as a *model of* and a *model for*<sup>7</sup> the social. This view of the world is intertwined with Science and Technology Studies' comprehension of science and technology as flexible categories that depend on the times and places within which they are produced and deployed. That is, science and technology are context and time specific in the sense that both shape, and are shaped by, social and individual circumstances that they encounter with and through time. In other words, I am committed to Casper & Koenig's (1996) call for a thorough research of biomedicine as ethno-medicine, taking western medical technologies as fundamental analytical concerns given that 'technology use in medicine cuts across social, cultural and corporeal boundaries' (1996: 524). In this same line of thought, Georges (1996) calls for scholars to regard technology and science as cultural products, which are by no means neutral or static. Neither possess authoritative knowledge from the start; rather, the authority is acquired by various means that can be traced back in a given technology's history in any society in which it happens to appear. These considerations, when translated into this research, mean that I attempt the task of unravelling the interaction between amniocentesis usage, the practice of selective abortion, abortion de-penalisation, and how these practices relate to the wider socio-cultural and historical reality of Colombian society in relation to attitudes towards people with disabilities.

Correspondingly, I follow Mol (2002: 32) in studying 'when a disease is being done' by actors, practices, intervention, objects, institutions, and politics; to look at how reality is multiple, or how it multiplies when one examines how conditions or technologies are enacted day to day. I do so in particular when looking at the category of *incompatibilities with*

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<sup>7</sup> The notion of a *model for* and *model of* is borrowed from Clifford Geertz' (1973) approach to religion.

*life*, also referred to as *conditions that make life unviable*. I have examined how such a category becomes or stops being in practice, and how it is enacted by different participants in different settings (the clinic, the genetics lab, the lawsuit, the de-penalisation sentence, the public discussion of abortion de-penalisation, and within families). I did not want to leave such a category unanalysed for, as Mol says, 'leaving "disease" in the hands of physicians alone is a political weakness' (2002: 22), but also because objects (or medical categories) 'come into being – and disappear – with the practices in which they are manipulated' (2002: 5). Addressing *incompatibilities with life* in this way allows me to reveal its multiplicity, and thus it is possible to problematise it.

Thanks to the extensive existing research on amniocentesis, we know today that decisions regarding whether or not to accept the exam, as well as decisions regarding the future of a specific foetus, are informed by a myriad of factors that range from the medical encounter with the genetic counsellor, to cultural values and personal expectations regarding antenatal life, pregnancy, parenthood, and disability (c.f. Marteu & Drake 1995; Press & Browner 1997; Mitchell & Georges 1997; Rapp 2000; Brookes 2001; van der Berg et al. 2005; Amhed et al. 2006). From the literature it is also possible to gain a clearer idea of what the impact of amniocentesis could be on pregnant women and their pregnancy experiences, for it adds, as suggested by many, anxiety to an already anxious process (c.f. Rapp 1997; Marteu & Drake 1995; Brookes 2001; Ahmed et al. 2006). On the other hand, many authors have pointed out that the technologisation of pregnancy has reduced the opportunities women have to reject the permanent use of 'new reproductive technologies', due to pressures coming not only from medical professionals but also from peers, family members, and society (c.f. Petchesky 1987; Rothman 1987; Mitchell & Georges 1997; Rapp 2000). Research focused on providing a wider understanding of antenatal diagnosis has also been paramount for comprehending the extent to which access to foetal genetic information, intended for reproductive decision making, reproduces socio-cultural readings and depictions of the meaning of disabilities, as well as of people with disabilities (Hashiloni-Dolev 2006). This makes it even harder to achieve proper social integration and much needed citizenship recognition for the population with disabilities (c.f. Marteau & Drake 1995; Shakespeare 1998, 1999).

In combination, Science and Technology Studies helps to address these questions from a different and enriching perspective, as this discipline allows for the problematisation of sciences and technologies as constructed by individuals responding to specific interests (c.f. Haraway 1988; Latour 1999). It also provides the grounds for stating that the mobilisation of technologies, and categories produced by them, are 'at the heart of enacting (possible) worlds and possible links between individuals', given that 'technologies, once put into practice, produce categories and sites of intervention and lead to particular configurations, both of human and of objects of medical intervention' (M'Charek & Keller 2008: 62, 64).

Furthermore, Science and Technology Studies enables an understanding of the authoritative stance of scientific knowledge production as something achieved, rather than an inherent fact (c.f. Georges 1996; Mitchell & Georges 1997). Perhaps most importantly, this discipline provides the tools for seeing sciences and technologies as produced by humans, hence, their development is imperfect, incoherent, and contradictory, despite the sense of organisation and coherence that science and technology have in public performance (Latour 1999).

Disability Studies also provides a complementary perspective, especially proponents of the social model of disability, who provide a social approach to disability and rich ground in which to put genetics, along with medicine's categorisation of *able/disabled*, into perspective. The relevance of this model is that it advocates on behalf of people with disabilities based on their individual needs, as opposed to ableistic oppressive ideologies which advocate "fixing" or "correcting" people with disabilities, in order to "fit" the designs of inflexible systems and standards (Castañeda & Peters 2000: 320).

In such a framework, the social model stresses society's role and responsibility in maintaining and producing 'inhibiting structures, which overvalue economic productivity, undervalue alternative social contributions, and attach positive and negative associations to the relative terms of independence and dependence' (Castañeda & Peters 2000: 320).

Nevertheless, and as highlighted by Shakespeare (1998: 670), ‘while social oppression is the main problem for disabled people, impairment<sup>8</sup> is also a significant issue, and one which it is important to discuss and deal with’. This is to say that even though disabilities are socially produced, one cannot disregard impairment, for people with disabilities must tackle both. To ignore impairment as a medical condition or disability as a social product is to reduce the complete embodied experience of disability-impairment to one or the other, and so overlook the complexity which disabled people are confronted with (Shakespeare 1998, 2008).

Disability Studies has also offered a concrete critique of antenatal diagnosis (c.f. Shakespeare 1998; LeBreton 2004), on the basis of the total focus on medical impairment, biology, and genetics which it enables. That is what LeBreton (2004) has referred to as genetic fundamentalism, which is surrounding today’s understanding of health, disease, and to a great extent identity. Such a fundamentalism leaves little room for comprehending disease and disability on a cultural basis, or further, as cultural constructs. The supremacy of the gene helps to reinforce long lasting notions of biological superiority of one human group over another. Genetic fundamentalism – by defining individual and collective identities, determining medical conditions, and redefining what constitutes healthy or ill – overlooks the role of cultural and social conditions within which these groups and diseases happen to take place. Therefore, genetic determinism makes it virtually impossible for a change or a growth in opportunities (whether political, educational, social, or economic), given that *what is inherited is inherited*. In other words, genetic technologies are producing an illusion of universal determinants that overrule cultural explanations for diversity, and provide the grounds for perpetuating ideals and beliefs regarding differences between *fit* and *unfit* individuals, and the archetypical life of both. To use Shakespeare’s words, ‘The boundaries between health and disease are altered, and social experience is increasingly ‘geneticised’’ (1998: 3).

Thus, in order to avoid either the hyper attention to genes and thus minimize the role of socio-cultural possibilities and realities, or overstressing the role of society in determining

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<sup>8</sup> According to Shakespeare (2008) ‘Disability is always an interaction between individual factors—predominantly impairment, aspirations and motivations and contextual factors—environments, policies, barriers and so forth’ (12), whilst impairment refers more to the biological and medical dimensions of a given condition. Nevertheless, ‘there are process of social definition and meaning inherent in the categorisation of impairment, and in the identification of disabled people’ (13).

a disability and so ignoring a medical impairment, one must understand disability at the crossroads of health and society (Shakespeare 1998).

In order to explore the abortion de-penalisation process and Sentence in Colombia, I have used the theoretical insight of Law and Anthropology to articulate individual practices with law changes and the definition of rights, and more importantly, Human Rights. That is, I have relied on theoretical contributions from this discipline, valuable for their ability to treat law and its relation to science as cultural products. This is relevant because abortion was de-penalised on the basis that by not doing so contravened a number of women's human rights.

The relevance of approaching the process of legal changes, in this case abortion de-penalisation in Colombia, is that a close relationship exists between law and the socio-cultural context in which it exists: they are mutually constitutive of one another (c.f. Moore 1983; Delaney 2001; Donovan & Anderson, III 2003). 'Law is part of social life in general and must be treated analytically as such' (Moore 1983: 218). Furthermore, '[t]he very idea of law can be seen to be reliant on a particular conceptions of humanness ... It is fundamentally committed to a particular view of the subject' (Delaney 2001: 488). To analyse law from an anthropological and Science and Technology Studies perspective means that concepts which are seen and treated as being utterly legal (and universal) are rendered as social products and producers of society.

One example of such a universalising concept is that of human rights (Donovan & Anderson, III 2003: 144). Human rights and the discourse surrounding them have been constructed as universal, neutral, and right by definition. However, the concept of human rights is particularly problematic in one basic and specific aspect: it defines neither what counts as a "human" nor as "rights" (Donovan & Anderson, III 2003). However daring it might seem to problematise such a defended category, it is important to bear in mind that neither "rights" nor a "human" are static universal categories (Delaney 2001; Donovan & Anderson, III 2003). In this sense, the assumption that human rights (as a single or as separate categories) are self-evident, is problematic. Before blindly accepting what appears obvious, one must ask who is being included in such a category and who is being silenced. The concepts of "human", "rights", and "human rights" are produced and reproduced in

different times and spaces, and their definitions fluctuate according to social imaginaries, socio-cultural and historical contexts, hegemonic discourses, and scientific innovations (Delaney 2001; Donovan & Anderson, III 2003). Of particular relevance here is the relationship between law and science and its role within the discourse of human rights, which has not only legal consequences the world over, but also enforces socio-cultural changes in particular (local) settings.

Interestingly, both law and scientific knowledge are represented and understood as being self-evident, neutral, universal, in search of the common good, and having no particular relation (in practice or development) to one another (Thorpe 2008). Yet, both law and science search to control and delimit the ever changing category of 'nature', and in that respect the category of 'human'. Law is a discourse that creates and recreates ideas of nature and humanness; law is also a set of institutions in which the discourse can be enacted; and, very importantly, law is power and it demands obedience from the humans it defines (c.f. Delaney 2001). In turn, science and scientific innovations not only recreate and re-delimit the boundaries of nature and humanness, but also respond to and raise political interests and disputes, which might be mediated by law or might produce social upheaval that can lead to changes in law (c.f. Thorpe 2008).

In this light, the matter of concern here – amniocentesis – is a good example of how the changing categories of nature and human, enabled and produced by law and science, are profoundly intertwined with one another. They respond to particular interests and belong to a specific discourse – modernity and liberalism (Thorpe 2008). Both are informed by cultural norms and social values, and the definitions of nature and human that they produce do have social consequences, which by definition exclude specific groups (c.f. Delaney 2001); groups that are created through the bill of rights and human rights, as I will show later.

## Methodological considerations

### *Doing research simultaneously on amniocentesis and abortion de-penalisation*

The following study is based on interpretative qualitative research, which relies on the ethnographic methods of direct social observations, interviewing, and case studies (Bonilla-Castro & Rodriguez Shenk 1995; Hardon et al. 2001), as well as on discourse analysis (Howarth 2000), and historical media and library archives.

From the perspective of an interpretative-constructivist approach, phenomena are not subject to objective, causal, or universal explanations (Howarth 2000). The concern here is with socially produced meanings, and the interpretation of such meanings, when approaching a social phenomenon, departing from the premise that each culture must be understood in terms of its own standards and values. In this context, the socially constructed world is approached by studying the dynamic relationships between social actors, which produce the social space as we encounter it (Gaonkar 2002). Within this framework, discourse is 'not merely what people say, but also what they do by saying something. It is 'a form of social practice that has specific goals or purposes and consequences' (Xu 2005: 21), and 'its action will be characterized by particular values with respect to particular groups of people' (2005: 67). Such a perspective recognises that discourses are not innocent, apolitical, or universal practices. Rather, they are 'a set of diversified and competing constructions of meaning associated with particular groups of people' (Xu 2005: 1).

In this sense, Foucault suggests that discourse must be approached from the person, or group of people who produce it, taking into account the given time and context in which the discourse takes place. For Foucault, analysis discourse regards 'the production of knowledge (rather than just meaning) through what he called discourse (rather than just language)' (Hall 2001: 42-43). Thus, 'discourse is about the production of knowledge through language' (Hall 1992, in Hall 2001: 44), which is by definition a collective act rather than an individual practice.

I conducted one year of fieldwork in Bogotá, the capital city of Colombia, during the year 2007. The city counts approximately 6,778,961 inhabitants (DANE 2005) and is

considered to be one of the most important metropolises in Latin America because of the permanent flow of information and people from all over the country, and from many different global locations ([www.bogota.gov.co](http://www.bogota.gov.co)).

Although the social and cultural reality of Bogotá cannot be compared with other places in the country, the fact that it is the governmental centre allows one to obtain an idea of the hegemonic discourses and practices categorised, or imagined, as *Colombian*. Further, health services offered by private health care providers in Colombia operate on a common basis, called the Obligatory Health Plan (POS – Plan Obligatorio de Salud). That means that in principle all health care providers should provide the same access to the same health care services. Given that the health care setting chosen for this fieldwork works at the national level, it made good sense to focus in Bogotá. Finally, amniocentesis is a service provided only in the main cities such as Bogotá, Cali, Medellín, Barranquilla, and Bucaramanga, to mention a few. Here again, to focus on the capital city seemed and proved to be a sensible option.

In terms of the participants in this study, after discussing the methodology with the chief specialist of the department in which the core ethnography took place, it was agreed to divide the population of users into two groups: those who are under the Obligatory Health Plan, meaning that they belong to the EPS, pay less, and have less procedures covered by their premium; and those who belong to the pre-paid system, who pay more, but therefore have greater access to amniocentesis, in terms of both money and information. It is also interesting that each group attends a different facility to have the amniocentesis and visit their Ob-Gyn. Nevertheless, as it will be shown in Chapters 3 and 5, that division turned out to be artificial.

#### *Multi-sited ethnographic fieldwork*

In order to be able to understand the practice of amniocentesis as it happens in clinics and to individual families, and also to understand abortion de-penalisation in cases of foetal conditions that ‘make life unviable’, this implied to a great extent doing two different fieldworks. Given that what interested me was the relationship between the two seemingly

different and separate topics, the methodology that best suited this fieldwork was what Marcus (1995) called multi-sited ethnography. This concept refers to an ethnography in which the methodical point of departure is that the complexity of a social phenomenon can be better understood if one observes different sites that relate to the same object of study. If one wants to approach a social phenomenon, observing different settings provides a better account of the complexity of the phenomenon. In addition to the multiplicity of sites, one needs to make use of a number of different research instruments that respond to the needs and characteristics of each site.

### *Hospital ethnography*

As Finkler et al. (2008: 248) point out: 'Hospitals are among the most fascinating spaces in contemporary society: they are complex; they are constantly changing'. In addition, The Hospital is a focus for ethnographers because it is a rich space of cultural production, in which cultural values gain strength, are re-shaped, or lose validity, thanks to, among other aspects, technological innovations (c.f. Van der Geest & Finkler 2004; Finkler et al. 2008; Zaman 2008).

From the growing field of hospital ethnography I found of particular relevance Renée Fox's (1974) groundbreaking work, conducted in the early 1950s, on chronically and terminally ill patients of metabolic disorders who volunteered to participate in a clinical experiment in search of a cure and an explanation for their condition. In that study, Fox elucidates how hospital dynamics are influenced by the interaction between patients and physicians, technological innovations, and the lived experiences of those who are part of the hospital, either as patients or physicians. She also shows how uncertainty plays a major role in medical practice, and on the role of being a patient under such conditions. These are issues that I found relevant, valid, and current to my own research, some fifty years later.

At the methodological level, Fox's work reveals the constraints entailed in conducting research in a setting in which people are constantly dying, suffering, or falling ill; a context in which medical uncertainty is counterproductive to human suffering given our trust in medicine and in medical technologies. This situation, Fox highlights, has

implications at the personal level for the researcher; as was also my experience. Being a medical anthropologist with no medical training working in a clinical setting generated the need to promptly develop emotional and cognitive coping strategies to face the hardship of being confronted with human suffering and anguish, as well as with body fluids, body parts, and bodily processes. In a sense, to face Eros and Thanatos within the clinical environment.

In order to understand amniocentesis practice and use I conducted a seven months long hospital ethnography in three locations within the Department of Maternal and Foetal Medicine of one of the most prominent private health care providers in the country, *Salud*<sup>9</sup>. I chose to spend long periods of time in such settings because this is the “natural setting” of amniocentesis (Brewer 2000), not only in terms of where the sample is taken, but also because it is where women and couples receive the news about their foetuses, and where abortion may take place. The Department is also the natural setting of the group of specialists in maternal medicine with whom I worked.

I started by going to the research locations only when an amniocentesis was scheduled. But as the time passed and I became more accustomed to the dynamics of the Department and to the staff, I spent more and more time at my main location within the Department – one of the clinics owned by the Health Care Provider – sometimes for more than eight hours at a time.

In all three different locations (attended by the same specialists) I observed everyday dynamics, the interactions between staff and different types of pregnant patients and between staff members, and I observed a total of sixteen amniocentesis procedures (of which four were determining foetal infection with toxoplasmosis<sup>10</sup>, and twelve karyotyping the foetus), one cordocentesis<sup>11</sup>, and two foetal surgeries. In addition, I was present at four medical meetings for *Antenatal Diagnosis of Congenital Anomalies and Advanced Therapy*, and at

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<sup>9</sup> This, as with all the names that I use throughout the text, is a pseudonym, except for the case of one specialist of whom I not only use interview material but also written material from his own publications. I address this point latter in the methodological considerations.

<sup>10</sup> Toxoplasmosis is ‘infection of humans with disease caused by a [toxoplasma](#) (*Toxoplasma gondii*) that invades the tissues and may seriously damage the central nervous system especially of infants’. Merrim-Webster online dictionary. <http://www.merriam-webster.com/dictionary/toxoplasmosis>

<sup>11</sup> As explained by the chief specialist at the Department, cordocentesis is an invasive procedure performed instead of an amniocentesis when the foetus is too big to puncture the amniotic sac. Cordocentesis is performed by extracting blood through the foetus’ umbilical cord.

twelve therapies for emotional support, provided to women and couples (and even families) once a diagnosis of foetal chromosomal or morphologic variation was confirmed to prospective parents.

As well as direct social observations at the clinics, I also interviewed the chief attending specialist, a senior specialist, students of the specialisation of maternal-foetal medicine (at that time three men), and the attending psychologist. Furthermore, I held multiple conversations with all staff members (specialists, fellows, residents, psychologist, nurses, and secretaries) over the course of the fieldwork.

Conducting hospital ethnography implies an enormous degree of flexibility on the part of the researcher. In particular, given physicians' hectic schedules interviewing was difficult to plan and to conduct; in fact, planning an interview soon proved to be a vain attempt. Specialists and fellows were unable to respond to the rigid timing of interviewing, for their everyday pace was too different. Therefore, we agreed on conducting the interviews whenever they found time to sit and talk. Two interviews took place during a slow afternoon in which few women attended the Department, and both were the longest that I was able to hold (one lasting two and a half hours). For the rest, interviews took place in the in-between time after one patient had left and the next one was being made ready for her check up. Thus, although an interview may have started at 14:00 and ended at 15:45, the recorded time might only have been about 40 minutes. In one case – the chief specialist – the only way we could find time for an interview was in a cab as he was going from one clinic to the other. Fortunately, Bogotá's traffic jams allowed us to have a fruitful conversation, and once at the clinic Dr Sossa spent another half hour for our interview.

Apart from the staff, I also interviewed 22 women, and in some cases their partners. At the clinic I met 19 women, sixteen of whom underwent an amniocentesis and one cordocentesis, plus three women who decided not to have the amniocentesis. Of these women and couples, I closely followed up one family, who generously involved me in what they experienced as a painful situation.

In addition to the interviewing and conversations, prior to having an amniocentesis I provided women with notebooks. The idea was that the women could use the notebooks as

diaries in which they would keep a record of their feelings, thoughts, and emotions while expecting amniocentesis results. As useful as this instrument may have been in other studies (c.f. Gerrits 2008), in my case it proved a failure. Women found the diary to be an extra and burdensome activity in their lives in which they did not want to invest time, and so many in our first meeting after the amniocentesis apologised for not having used them. One woman found the whole idea of a diary utterly boring and said: *'No, you keep the notebook, I won't write in it...that is way too tedious and boring'*. Only one woman did keep a diary for the first 5 days after her amniocentesis. However, because it was something that she was planning to show me, she used it as an opportunity to complain about the expenses of the exam, the pain she underwent, the difficulties she had in reaching the Department, and the fact that amniocentesis *'even though it was such a vital exam for the baby and for the mother'* was not covered by the POS.

Outside of the clinic, I interviewed three women about their past experiences with amniocentesis, some years previous. Of these three women, two had decided not to undergo the amniocentesis.

Because I wanted to gain a broader perception of the practice of amniocentesis, I interviewed two more specialists who worked at another clinic providing maternal-foetal medical services, but with a more limited practice (performing only the amniocentesis, and using a different sort of obstetric ultrasound). I have included their views on the practice, function, and usages of amniocentesis, as well as on selective abortion based on positive amniocentesis results. With one of these specialists, Dr Cifuentes, I held two interviews at 6:45 in the morning, before his practice started. However, such interviews could not last more than 20 minutes, for his first patients arrived at 7:00-7:05. With the other specialist, Dr Alvarez, who is the chief specialist in this practice, I was able to arrange an interview after three attempts, and we finally met on a Friday at 14:00. We were finished by 14:08. That was the shortest interview I held during my fieldwork.

Given that amniocentesis is a genetic exam, I found it paramount to include the perceptions and viewpoints of geneticists who are in close contact with it. Therefore I interviewed twice a geneticist considered the founding father of genetics in Colombia, who was also the first to karyotype from a sample from an amniocentesis, and also Dr Santos,

chief of one of the very few genetics laboratories in Bogotá. In addition, I interviewed Dr Tovar, the representative for Colombia in a Latin American collaborative group studying congenital malformations. This human geneticist is openly against amniocentesis due its relationship with abortion, and from time to time serves as a consultant to the Department in which I conducted fieldwork. Additionally, I interviewed geneticist Dr Clavijo, a friend's mother, who explained to me the basics of human genetics, of doing a karyotype, and of trisomies and monosomies in relation to chromosomes.

As important as the current practice of amniocentesis is, the history of amniocentesis in the country is equally important for it reveals continuities and changes that help to elucidate the complex dynamics of this technology. In order to reconstruct a history of amniocentesis in Colombia, I interviewed twice Dr Fernando Sánchez-Torres, the first Ob-Gyn practicing in Colombia to publish on amniocentesis in Colombia, accounting for the different usages of the exam and on his experience with it. His first publication dates back to 1972.

All of the interviews which I conducted, except for the two held with Dr Sánchez-Torres, were recorded on a digital voice recorder. I had planned to transcribe all interviews and I did transcribe five. However, when the time for analysing the information came, I realised that much of the emotions, context, and reality of the clinic situations and conversations, as well as the daily life of the women and their partners, specialists, and geneticists, would be lost if I detached the surrounding world from the words said by the interviewees. Therefore, and in order to recognise the salient topics of each interview, I listened to all interviews several times over rather than transcribing them, paying attention to and noting different issues.

All interviews and conversations were held in Spanish, and all translations are mine. Finally, all the names I have used throughout the text are pseudonyms provided in the attempt to protect the identity and privacy of all participants. Dr Sánchez-Torres is the only exception I have made: I decided to keep his actual given and family names because in Chapter 4 I move between interview and published material quotations. Therefore, to change his name would not only be misleading, but would also imply altering bibliographical references.

*Seminar and Forum ethnography*

There were two other activity sites for the ethnography. One was a permanent seminar, organised jointly by the bioethics network of the National University and the Ministry for Social Protection, with the intention of discussing the aftermath of abortion depenalisation, one year on. The seminars took place at the Genetics Institute of the National University every Monday from 7:00 to 9:00 am, and lasted from February until the end of May 2007. The spirit of the permanent seminar was to promote and enable an open and constructive discussion from the 'ethic-juridical perspective' of Sentence C-355/06 (Universidad Nacional de Colombia 2007a). I participated in the seminar from late April 2007 until late May 2007, when the seminar came to an end.

The second activity was assisting at the National Forum, where I received documentation produced by the scholars meeting in the permanent seminar. Once the permanent seminar had concluded, a National Forum was organised in order to bring to different parts of the country the discussion points that were addressed at the seminar. In Bogotá, the National Forum was held over two full days, from 8:00 until 17:00, on 31<sup>st</sup> May and 1<sup>st</sup> June 2007, at the Military University.

For both activities, an interdisciplinary group was summoned and civil society was welcomed to attend. The speakers at the two activities were representatives of the Ministry of Social Protection, Judges of the Constitutional Court, bioethicists, geneticists, gynaecologists, lawyers, physicians, philosophers, and representatives of the feminist movement.

As for keeping records of my observations during fieldwork, I kept extensive field notes of each day or activity that I observed.

*Archival research*

Finally, another method that I used was archival research. In order to account for the abortion debate and the public image of amniocentesis I conducted archival research on media coverage of these topics. With the help of my research assistant and friend, anthropologist Natalia Niño, I was able to gather 800 media articles; 207 articles correspond to the main national daily, *El Tiempo*, and 503 correspond to the opinion magazine *Semana*. These sources were approached and studied using the method of discourse analysis, as presented in the theoretical considerations. As *El Tiempo* and *Semana* are mainstream massive circulation opinion-information sources, I have treated them as being representative of a hegemonic viewpoint on rights, abortion, antenatal life, antenatal technologies, medicine, and science. Therefore, when analysing these media articles, I focused on how the abovementioned concepts are conveyed to the general public, and thus contribute to reinforcing, legitimating, or de-legitimising previous, current, or new understandings of the concepts.

The material gathered from *El Tiempo* was related to the years in which: a) either a law project or a challenge to abortion law were presented to the Congress or the Constitutional Court respectively (1979, 1994, 1997, 2005); b) the Colombian Constitution changed (1991); c) the Penal Code changed (2002); and d) when abortion was de-penalised (2006). The data date from 1979 until 2007. The key searched for and gathered issues were: abortion (n=123)<sup>12</sup>, amniocentesis (17), disabled people and disabilities (n=20), eugenics (n=7), antenatal diagnosis (n=20), and genetics (n=20).

With regard to the material corresponding to *Semana*, the material gathered dates back to 1982 and extends to 2007. The key searched/gathered topics were: abortion (n=150), abortion related only to foetal malformation (n=11), amniocentesis (13), malformed foetuses (n=56), disabled people and disabilities (n=13), eugenics (n=10), foetus (n=100), antenatal testing (n=40), and genetics (n=160).

In order to be able to elucidate and understand the roots of discrimination in Colombia I consulted library archives from the early 1900s, which contain documents from

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<sup>12</sup> n= being the number of articles.

the thinkers, educators, jurists, and physicians who conducted the eugenics movement, as well as the ones who constructed and implemented the hygienist movement – later ‘public health’ – in Colombia. The consulted articles, law projects, theses, and speeches addressed issues such as: eugenics; abortion; euthanasia; different conceptualisations of race; the worry of the degeneration of the race; physical education; puericulture; care of pregnant women; the neonate, the child, and the woman; pre-nuptial medical certificates; the role of the woman in securing and bettering the race; the place and understanding of the unfit (mentally, physically, and socially); and indigenous, black, and poor populations.

Most of the archival material was photocopied, however many articles were digitised. The very old and rare documents had to be read in special cubicles and I could only take notes. All information was organised by topic and all categories were analysed independently in a first round of analysis, though during a later phase all categories were analysed in relation to one another.

#### On the researcher – ethical considerations

Having come to this point in which the conceptualisation of the study and theoretical and methodological considerations have been addressed, I find it ethically relevant to provide a note on my role as researcher, and as the interpreter of the situations, interviews, conversations, exams, media articles, and archival documents that compose this research. I position my knowledge claims as part of my own stance regarding the research subject, for ‘positioning is...the key practice of grounding knowledge ... positioning implies responsibility for [one’s] own enabling practices’ (Haraway 1988: 587). Positioning is also important because, as pointed out by Blume (2000: 143), ‘the interpersonal relationships out of which an ethnography is constructed entail mutual obligations that, for ethical reasons, are to be respected. But subject’s stakes in ethnographic work – or expectations of the ethnographer – are various and may change’. Accounting for such changes, and ambiguities on the part of participants and myself, does justice to the ambiguous and shaded ambiance surrounding amniocentesis for foetal karyotype and selective abortion, as it happens to real people in real time.

As mentioned earlier, my position towards amniocentesis for karyotype and selective abortion had dramatically changed over the course of this study. When I started out this research I found both practices not only acceptable but, to some extent, necessary. However, before starting the fieldwork I realised that my enthusiasm about selective abortion must have a deeper, socio-cultural source. Thus selective abortion and my enthusiasm for it needed to be put into perspective, which helped me realise how problematic it can be to consider that, in everyday reality, there are lives more worthy than others in terms of fitness. Such a realisation became and stayed painful during and after fieldwork.

When the fieldwork started, so did the pain. As days passed by, I endured physical and soul pain (or whatever it is that hurts that is not in the physical body) observing amniocentesis procedures, abortion decisions, or medical meetings for discussing foetal diagnosis before or after abortions. It hurt watching women being pricked with long needles. It hurt witnessing how women were placed second by the Department's dynamics. It hurt when listening to their fear about the health status of their babies, and how their family future might be jeopardised if their baby was deemed "sick". Then pain sometimes turned into anger when I observed how abortion decisions were made, and when I listened to the arguments that families would be better off if a particular baby was not born.

All these feelings created an inner turmoil that placed me at a crossroads in which I needed to balance my own take on the aforementioned issues and the experience and viewpoint of the participants of this study, in order to fully comprehend the dimensions of the research question.

From one perspective, I came to view selective abortion as an attempt to provide one's offspring with the best of life, and spare children sorrow and difficulties. In that sense, amniocentesis and other antenatal technologies can be seen as blessings for prospective parents. Yet again, however, I was left with the questions of who and how can decide whose life is worth living; why "medical" disabilities are portrayed, seen, and experienced as being preventable and so "treated" through abortion; how normality should be understood, and what is the standard for normality. Framed by these questions, I have chosen to be very careful in the words I use in writing this dissertation. Wording such as 'chromosomal or morphological variations', 'chromosomal or genetic conditions', 'a foetus different from the

average', 'people with intellectual differences', and 'selective abortion', to mention a few expressions, as well as the use of italics for some words, are the product of a long and cautious process aimed at not reproducing discrimination, either by disrespectfully labelling individuals, or by offensively relying on euphemisms that are as harmful as the former ways of referring to people and practices.

However, ambiguities during fieldwork and whilst writing went beyond my very personal experiences. During fieldwork I faced important power relations between the different participants of this study. One such example was the fact that, at the request of the chief specialist of the Department, Dr Sossa, I was supposed to wear a white coat at all times when present at any of the Department's locations. For Sossa, my wearing the white coat would provide women and couples with the comfort of talking with a staff member of the Department. Although I gave in and wore the white coat, I made sure that the first thing I did when introducing myself was to make explicit that I am not a medical doctor, and thus there were many issues concerning their pregnancy that I initially completely ignored and did not understand. In addition to this vital clarification, I stressed many times that their involvement in this research was absolutely voluntary, and that if they decided either to not participate or to withdraw from the study, neither decision would affect the care and services they would receive. I also iterated that all the information they provided me with was confidential, as was the information I gathered from the medical practitioners.

This last part of keeping information confidential turned out to be a difficult endeavour. Sometimes women would phone me at home to ask me if I knew something about their babies. In most of the cases where I did, I chose not to disclose this information. The reason is a very simple one: given my lack of medical knowledge I did not want to start a conversation about a diagnosis of which I had no real awareness of what it meant. If I had disclosed such information, the support women were seeking – and in many other ways found in me – would become harmful to them, and it would not only have turned my role into an entirely intrusive one, but would also have been utterly irresponsible. Similarly, I took the same stand in relation to disclosing personal information of the women and couples to staff members. Finally, I never partook in the decision making process regarding an abortion.

As exposed earlier, in the writing process as well as in the fieldwork, I was faced many times with ambiguities about my own position, and towards women's or couples' decisions regarding selective abortion. Such an ambiguity is demonstrated in my commitment to showing the grey areas of amniocentesis in relation to selective abortion, given that both practices and technologies are neither unequivocal nor suppose an easy decision free of pain. To account for such an uncertainty, which meant recognising my own, was also not an unequivocal or pain free process. The reason why I choose to report such a struggle is because I am responding to Haraway's call for 'the view from a body, always a complex, contradictory, structuring, and structured body, versus a view from above, from nowhere, from simplicity' (Haraway 1988: 589).

In this sense, I must assert that as much as I have altered, transformed, or, as Rapp (2000: 18) says, 'contaminated' the context that I studied and the data I gathered by the simple act of 'being there', I was also transformed by the objects and individuals of this study (Haraway 1988: 592). Hence, both the study with its individuals, practices, objects, situations, and I are mutually constituent of one another.

### Reading this book

The book is divided into two parts. The first accounts for the wider socio-cultural and historical context, and thus addresses the abortion debate and de-penalisation, the history of amniocentesis in Colombia, and the eugenics movement in the country. The second deals with the actual experience and daily life of amniocentesis at the Department on the one hand, and with the personal experience of 22 women that were in contact with amniocentesis on the other.

The chapter distribution in Part I is as follows. Chapter 2 is an overview of the development of the abortion debate, in which I pay careful attention to Roa's lawsuits that triggered a new version of the debate and made possible abortion de-penalisation. I analyse and problematise the features of this debate, and also analyse Sentence C-355/06, by which abortion was de-penalised. I focus on the case of 'foetal malformation that makes life unviable outside the uterus' (Sentencia C-355/06: 287) and highlight the central role played

by antenatal technologies in achieving and articulating this case of abortion de-penalisation. In Chapter 3 I analyse the permanent seminar and the National Forum as public nation building scenarios, in the year after abortion de-penalisation, and look at how actors such as geneticists and specialists in maternal foetal medicine, who are in close contact with the possibility of foetal diagnosis, shape and are shaped by abortion de-penalisation.

Finally, Chapter 4 addresses two interrelated topics: the history of amniocentesis in Colombia, and the history of the eugenics movement as it happened in this country. By focusing on the history of amniocentesis in Colombia, I am able to show how the technology has changed over the years given technological innovation in the fields of obstetrics and human genetics, while at the same time it has provided the means and the possibilities for transforming such fields (c.f. Latour 2002). To highlight the nature of the eugenics movement in Colombia, a link between hygiene, eugenics, and obstetrics becomes evident, which allows me to articulate today's individual reproductive choices with long lasting national ideology, and socio-cultural discriminatory practices and attitudes towards specific groups of people, or more precisely, towards people with intellectual and cognitive differences.

Part II refers to the actual practice of amniocentesis, and to the individual experience of being confronted with the exam and with the possibility or reality of being faced with a positive amniocentesis result. Thus in Chapter 5 I start by accounting for the current reality of amniocentesis. I focus on the problematisation of maternal-foetal medicine as a practice in which the category of patient is mobilised in various ways and allocated differently to the foetus and to women. The focus of the volatile category of patient, as it takes place at the Department, is twofold. Firstly, it highlights the secondary – almost invisible – role of women in the larger process of foetal diagnosis, and secondly, it elucidates the way in which disabilities are constructed within the medical environment as a family disruption and as a life mishap. Such a construction of disabilities and of people of disabilities allows for a legal abortion in cases of chromosomal variation.

Finally, in Chapter 6 I address the individual experience of first deciding whether or not to undergo an amniocentesis, and second, when relevant, of deciding whether or not to bring the pregnancy to term after a positive amniocentesis result. Through individual

narratives I underscore that although there exist salient socio-cultural attitudes towards amniocentesis and selective abortion, the individual experience of a specific pregnancy plays a major role in deciding which way to go, rendering the individual relationship with either practice difficult if not impossible to generalise. In this chapter I therefore relativise both technological and socio-cultural determinism, to open space for the individual experience as a dynamic constituent of the socio-cultural and historical context.