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

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## Conclusions Achieving the desirable nation

Somewhere in the middle of my fieldwork, at one of those moments in which information was in abundance but structure lacking, I was stuck in a huge traffic jam, the kind that are usual in Bogotá during the afternoon hours. At that point people's expressed unwillingness to bring up children with disabilities had been a constant and recurrent theme. So too was the view, widespread among medical professionals, that people with disabilities – especially those with cognitive variations associated with conditions such as Down syndrome – are inherently burdensome.

On that day, as on many others, I was going from one clinic to the other. There were several women and couples scheduled for psychotherapy with Jimena, all of them *diagnosed with a malformed fetus*. At one point during my journey the taxi spent some 10 minutes at a standstill on the perimeter of the city's coliseum and stadium, giving me time to look at the banners announcing the Para-Olympics that were taking place in Bogotá during June 2007.

I was contemplating a curious contradiction. I was going to be present in four psychotherapy sessions aimed at helping women and couples cope with the assumed *trauma* and *shock* brought about by their fetuses' chromosomal or morphological status, an assumption based upon the prevalent view of people with disabilities as sorrowful and burdensome. Yet at the same time Bogotá was hosting this major international event that recognised and praised different abilities in people. Then the taxi driver, who had been completely silent all journey long, uttered with utmost distaste, more to himself than to me:

What is this? Why anyone would like to come and see this bunch of retarded people in the Olympics ... this is outrageous. They want to show this show of freaks as if they were normal. And what can these people [with disabilities] do? Only ridicule, just that, what else? ... They are just a bunch of retarded people, freaks. As if we did not need the public funds to be spent in more useful ways...

Although I received this comment as violent and painful, it also helped to articulate within the wider socio-cultural structures the situation in which the individual pregnancies and practices, which I was observing and studying, were taking place on a daily basis at the Department. This comment helped me to make concrete the notion that there exists an imaginary of people with disabilities and stigmatised differences, either physical or

cognitive, as undesirable individuals (on whom public funds should not be spent). My experience with the taxi driver, who felt repulsed by such a thing as the Para-Olympics and outraged that his share of public funds were being wasted on a worthless endeavour for *worthless people*, served as an entry point for connecting the individual with the social; the structural discrimination against people with disabilities that exists, although tacit, in Colombian society, with the habitual practice of aborting fetuses with chromosomal variations that may suppose cognitive variations.

In the preceding chapters I have shown that biological, medical, and social categories are mutually constitutive. This was done by exploring the connections that exist between amniocentesis, selective abortion de-penalisation, and selective abortion practices as they happen in the current Colombian context. I was able to show that practices and social imaginaries are intertwined and articulated via the category of 'conditions that make life unviable', also known as 'incompatibilities with life', a category that refers not only to life in biological terms, but also in terms of social life (and even lifestyles). Thus, selective abortion de-penalisation not only made discrimination legal, but also made it legal to choose one's offspring in relation to a life plan.

Selective abortion de-penalisation contributes to the endeavour to achieve a desirable nation at various levels. The religious injunction against abortion has been challenged in ways that overlapped but did not displace segmented views and practices regarding the notion of the modern state as respectful of human rights, working to improve indicators of public health, and mindful of women's right to reproductive choice. The particularities of de-penalisation, allowing abortion in certain cases, for example when the foetus has a condition 'incompatible with life' or 'that makes life unviable', fits the ideal of a modern, respectful nation in which women are able to make reproductive decisions, and also where women are not subjected to *cruel and inhuman treatments and torture* – such as giving birth to and raising a child different from the norm is supposed to be – as stated in de-penalisation Sentence C355/06.

Similarly, given the widespread use and interpretation of amniocentesis as a tool for identifying fetuses with chromosomal variations, in order that they may be aborted, this technology can be seen as helping to achieve a particular sense of the 'desirable nation'. Amniocentesis responds to, whilst also providing elements for, a Colombian anthropological

ideal of individuals, families, and citizens that has roots deep in Colombian history. It is an ideal inflected by notions of race, a key element in building an imagined community. But this ideal has folded into it a social imaginary of people with disabilities as unproductive, degenerate, and unworthy of community membership. In Colombia, amniocentesis has become embedded in a socio-cultural context in which people with conditions (of the type that the technology can identify) have been seen as barriers to the realisation of this nationalistic ideal. It is an ideal in which only able and productive people who will contribute to *modernising* the country have a place.

The way in which amniocentesis performs and is performed today, in combination with the practice and de-penalisation of abortion of fetuses catalogued as having conditions ‘incompatible with life’ (and the very flexibility and malleability of the category ‘incompatibilities with life’) helps bring the Colombian eugenic ideal of a desirable nation within reach. It does so in at least 4 senses. Firstly, by the way in which amniocentesis performs and is performed, by the categories it enables, and by the functions attached to it, it responds and contributes to the perpetuation of the imaginary that people with cognitive differences are undesirable, burdensome, worthless people, to individual families and society alike. Secondly, there is a widespread perception that Colombia is a country that takes inadequate care of its citizens and fails to distribute public funds properly, thus perpetuating structural violence and inequality. These perceptions also reinforce the idea that the country and the nation would be better off without people deemed as useless and expensive. This latter point relates to the third issue, which is a generalised understanding of Colombia as a country that needs to *develop*, *progress*, and *modernise*, in order to meet international standards of progress and modernity. As seen in Chapter 4, people with cognitive differences – as well as black and indigenous people – are perceived as hampering the possibility of progress and development. Finally, what makes the practice of amniocentesis – in relation to the practice and de-penalisation of selective abortion as it happens today – profoundly Colombian and eugenic is that all the abovementioned conceptions, perceptions, and practices remain at the level of medico-social prescription. The imaginary of people with cognitive differences, and the abortion of fetuses with conditions that may lead to such, are deep rooted and well established ideals and practices amongst the Colombian population. Though just as with early eugenic thought, and the practices that in

the Colombian context derived from it, there have been no explicitly eugenic public policies. That is, eugenic thought and practices are not exercised from above. Rather, they are integrated within, and perpetuated and distributed by, the medical profession and its heterogeneous practice towards patients and the population (c.f. Foucault 1976).

Abortion de-penalisation in the cases analysed in this research contributes to perpetuating such practices and attitudes. But just as there was no pressure to enact eugenic legislation in Colombia in the early and mid 1900s, so today no one demands governmental policy that would encourage the abortion of foetuses with chromosomal or morphological variations. The decision to abort, however socially and culturally informed, is left within the private sphere of women and couples. And yet, despite the apparent individuality of abortion decisions, these decisions have profound socio-cultural consequences. Collectively they are shaping the makeup of society today. In Rapp's (2000: 3) words, women confronted with amniocentesis are being made into moral pioneers who choose who is good enough to enter the human community.

In this particular context, medical professionals such as obstetricians, gynaecologists, specialists in maternal-foetal medicine, geneticists, and public health specialists are an instrumental part of the realisation of the aforementioned population ideal. Antenatal technologies such as amniocentesis, obstetric ultrasound, and cordocentesis, to mention a few, are doubly valuable for these medical professionals. On the one hand such technologies attest to *modern*, up to date practice that can hold up its head internationally. On the other hand, such technologies enable medical professionals to better discharge their responsibilities to the collective through the help they offer in achieving a desirable imagined community.

But technologies and the categories they produce – like amniocentesis and 'incompatibilities with life' – are not fixed or neutral in their uses and functions. The context in which actors and practices are embedded (and which they produce) shapes and is shaped by the deployment of and meanings attached to technologies. Similarly, as I have showed in this text, the category of conditions 'incompatible with life' is plastic and multiple (Mol 2002), subject to many interpretations and many realities depending on the different situations in and actors by which such a category is enacted.

Uses, enactments, and interpretations of amniocentesis results are shaped by the structure of the health care system, and by physicians' understandings of their roles, responsibilities, status, and professional ethics. Firstly, amniocentesis is a technology that is assumed to lead to what is considered to be the exercise of a woman's right to reproductive choice. However, the health care system in Colombia is marked by unequal access to the exam, enabling only those able to pay for it to exercise their human and women's rights. Secondly, given physicians' roles and status, they see in amniocentesis a valuable tool for their patients, hence they expect women to want the test, especially those clustered in medically defined *risk* groups. However, their views on abortion, disabilities, and 'incompatibilities with life' are also complex and varied. This is visible in the way in which physicians cope, in practice, with the different patients they deal with (women and fetuses). Yet, as shown in Chapter 5, physicians exhibit a visible failure to understand what the diagnostic process itself means for women, and how, when a foetal condition is diagnosed, women, once backgrounded in the antenatal scenario, are then made into the main decision makers regarding the future of their pregnancy.

When it comes to women and families it is necessary to state that different attitudes to the tests and to the possible implications of a positive result cannot simply be divided between 'pro-choice' and 'pro-life'. Attitudes and stances towards amniocentesis and selective abortion are far more complex than that, for they are influenced by previous experiences, life circumstances, and life trajectories. Thus when confronted with amniocentesis and its positive result, women and families bring their own (very broad) understandings of 'incompatibilities with life' to bear in their interactions with physicians. In addition, as shown in Chapter 6, women and families want to fashion their individual lives as they wish, and believe themselves able to do so, either by choosing to not have a particular child, by wanting to prepare themselves for the arrival of a child with disabilities, or by choosing not to have an amniocentesis at all.

In the context of amniocentesis and abortion decision making, the notion of 'incompatibilities with life', as articulated in practice, is the result of negotiations between women (and couples) and professionals, in which each draw (differently) on their inherited understandings, and on current notions of rights, choice, and reproduction. The outcomes of such negotiations are thus, in part, a result of the plasticity of two things – a technology that

promises normality, and the crucial concept of ‘incompatibilities with life’ – and have as an aggregated outcome the further devaluation of people with disabilities, particularly those with cognitive differences.

Nonetheless, following the rhetoric of estimating people in terms of the burden and costs that they suppose for a country like Colombia – a society stricken by structural violence; with ingrained discrimination not only against people with cognitive or morphological differences, but also based on class and ethnicity; with unequal access to education, health care, job opportunities; and with inherent governmental corruption – a fundamental question remains. Would it not be better to strive for an inclusive and respectful society that praises, and thus benefits from, the different abilities of its citizens, with or without disabilities, with or without a chromosomal count of 23 evenly distributed pairs? Would Colombia not be a more desirable nation if all its citizens could be included in building it?