

Reproductive Rights and Cognitive Disability: Analysis of Sterilization Policies in Colombia

By

Gladys Adriana Becerra

Submitted to

Central European University

Department of Gender Studies

In partial fulfillment of the requirements for the degree of Master of Arts in Critical Gender Studies

Supervisor: Prof. Katja Kahlina

Second Reader: Prof. Judit Sandor

Budapest, Hungary

2015

ABSTRACT

This thesis presents an analysis of Colombia's legal stance on the surgical sterilization of people with cognitive disabilities, through an examination of the Colombian Constitutional Court theory on cognitive disability and autonomy. I suggest here that the Court's framing of involuntary sterilizations as a mechanism that protects people's physical and moral integrity conditions the exercise of sexual and reproductive rights in Colombia to models of individual autonomy that rely on negative tropes around disability and cognitive impairments, and which exclude disenfranchised groups from societal participation and do not recognize their moral worth. In addition, this thesis explores the importance of incorporating disability as a category of analysis and a system of representation into feminist theory, and presents some recommendations to national legislations in order to create better decision-making frameworks for people with cognitive disabilities and mental illnesses.

Keywords: cognitive disability, intellectual disability, forced sterilization, feminist disability studies, crip theory, supported decision-making models, individual autonomy

ACKNOWLEDGMENTS

I want to thank my supervisor, Katja Kahlina, for her constant guidance throughout the development of this research, and my parents for their love and support. I also want to thank the great friends I have made in Budapest: Alex, Iva, Melinda, Jovana, Tania, Judith and many others; meeting them was the best part of this experience. Finally, I want to thank Bálint for his love and his patience in the course of writing this thesis, and for being the best partner I could ever ask for.

TABLE OF CONTENTS

INTRODUCTION	1
Research Design and Methods.....	4
CHAPTER 1: THEORETICAL FRAMEWORK.....	7
Feminist Disability Studies	7
Feminism, Disability and the Mind	11
Cognitive Disability and Autonomy	15
Crip Theory	17
CHAPTER 2: STERILIZATION, CONSENT, AND THE MYTH OF INDIVIDUAL AUTONOMY	21
Autonomy	22
Capacity of Enjoyment	24
Capacity of Exercise, Flexibility and Informed Consent.....	31
CHAPTER 3: SEXUALITY AND DISABILITY IN THE CONSTRUCTION OF STERILIZATION POLICIES	44
The problems of liberal feminism in analysis of cognitive disability.....	46
Sexual Stereotypes and Disability	51
Violability of disabled bodies	56

“Personal Safety” and the danger of puberty	60
CHAPTER 4: EXPLORING ALTERNATIVES: SUPPORTED DECISION-MAKING MODELS	
.....	66
PATH (Planning Alternative Tomorrows with Hope).....	68
Supported Decision Making Agreements	69
MDAC’S Recommendations	71
CONCLUSION.....	74
REFERENCES	77

INTRODUCTION

“Disability is the most human of experiences, touching every family and- If we live long enough – touching us all”

Rosemarie Garland-Thomson (Garland-Thomson, 2011, p. 17)

In 2010, Colombian Congress passed bill No. 1412, which offers free surgical contraception (vasectomy or tubal ligation) for all adult citizens as part of a nationwide strategy to promote responsible parenthood in the country. This law allows for the possibility of sterilizing adults with “mental disabilities” (art. 5) as long as the request is presented by their legal guardian and counts with judicial approval, and declares it illegal to sterilize minors even if they have passed the age of consent, which is 14 in Colombia . A later judicial review from the Colombian Constitutional Court placed this norm at the center of a social controversy surrounding the reproductive rights of people with cognitive disability¹, because it declared the constitutionality of limiting permanent contraceptive methods to adult citizens except in cases of minors with “severe or profound”

¹ Given the wide variety of diagnoses targeting mental functions and the existence of different ways of referring to them, in this thesis I will simplify matters by using the expression “cognitive disability”, in order to refer to the range of human variance concerning intellectual and cognitive functions.

disabilities, who could be sterilized with the same requirements as adults with disabilities. Ruling C-131 of 2014 applied a theory developed by the Court in 2002 and maintained ever since, which restricts the recognition of sexual and reproductive rights to standards of able-bodiedness and liberal ideals of rationality and independence that exclude people with cognitive disabilities.

Though the Court has been allowing sterilizations of adults and minors (14 years old and older) since its first decision on the subject in 2002, ruling C-131 of 2014 took the matter to a higher level by declaring it constitutional not just for particular cases but for all people diagnosed with “severe or profound” disabilities, under the argument that “the decision to be subjected to a surgical contraception procedure ensures more dignified living conditions for those who cannot make decisions related to the exercise of their reproductive freedom, and who can be exposed to forced pregnancies in detriment of their dignity and personal integrity”² In response, national and international organizations and disability advocacy groups published a statement rejecting the Court’s decision, claiming that sterilizations are not adequate prevention measures from sexual abuse, and that Colombia is not recognizing its international obligations regarding the protection of people with cognitive disabilities³, particularly art. 23 of the UN Convention on the Rights of

² Original in Spanish: “La decisión de someterse a anticoncepción quirúrgica asegura condiciones de vida más dignas para quienes no pueden tomar decisiones relacionadas con el ejercicio de su libertad reproductiva y que pueden verse expuestos a embarazos forzados en detrimento de su dignidad e integridad personal”.

³ Colombia’s relationship to the protection of people with disabilities has evolved throughout the 20th century, especially after the expedition of its current Constitution in 1991. The State has ratified most if not all of the main international Conventions and instruments for the protection of people with disabilities, such as the Convention on the Rights of Persons with Disabilities (2011), the Convention on the Elimination of All Forms of Discrimination Against Women (1982) and the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities (1999) among others. Art. 93 of Colombia’s Political Constitution gives human right treaties constitutional rank, that is, they are of automatic enforcement as soon as they are ratified and previous local and national regulations will be interpreted according to them. If doubts arise, it is the competence of the Constitutional Court to determine whether a particular norm follows or violates both the National Constitution and ratified international conventions.

Persons with Disabilities that mandates ratifying state members to respect the fertility of people with disabilities on the same circumstances as everybody else. (Centro de Derechos Reproductivos, 2014). National coverage of the debate presented testimonies both from parents that welcomed the measure due to concerns about transmission of genetic disorders, financial duress, and the impossibility to provide permanent protection against sexual assault (among other reasons) and others who would not authorize it because they see it as an extreme violation of their children's right to consent (Linares Gomez & Fernandez, 2014). Doctors, on the other hand, manifested their satisfaction with the Court's theory, arguing that people who cannot take care of themselves can take of others even less. Others considered surgical contraception an adequate measure, but expressed the need for complementary measures, like clinical psychologist Patricia Gaviria, who said "sexual intercourse with a person with severe mental disabilities is in all cases sexual abuse. Instead of thinking just about sterilization (society) needs to find ways to protect these children and teenagers from mistreatment" (Linares Gomez & Fernandez, 2014)

In this thesis, I want to take a closer look at the idea of surgical sterilization as a suitable measure of protection for people with cognitive disabilities and, more importantly, to the arguments employed by the Court in order to legitimize the procedure. Ruling C-131 of 2014 is only one of the most recent articulations of a well-developed judicial precedent the Court has been working with since 2002, one which relies on specific theories and constructions of autonomy, sexuality, and disability. In this sense, my analysis will center around three main questions: (i) how is the

sexuality of people with cognitive and intellectual disabilities constructed and deployed by Colombia's current system of legal guardianship, particularly in the case of surgical sterilization?

(ii) What are the implications of framing forced sterilizations of people with disabilities as a measure aimed at protecting their sexual autonomy? and (iii) How do gender, disability and class intersect with each other in the creation of sterilization policies aimed at promoting responsible parenthood strategies? Through these questions, I seek to shed some light on the ways in which stereotypes on disability, gender and sexuality are naturalized in Colombia through judicial decisions, and how protection discourses in practice marginalize people with cognitive disabilities from public spaces, and further the divide between "normal" and "abnormal" subjectivities.

Though my analysis is limited to Colombia (since this is the context I am familiar with), I believe that the insights taken from it are relevant for examinations of disability and reproductive rights in many other countries and political systems, especially because sterilization practices on people with cognitive disabilities count now with official approval, instead of being an illegal procedure carried out by caregivers and medical practitioners. This project also attempts to use a specific case study in order to provide a feminist critique of the figure of legal guardianship for people with cognitive disabilities, applying an intersectional analysis to a legal theory that is just beginning to take hold in Colombia and other parts of the world. In this sense this thesis will hopefully produce recommendations for future policies on cognitive disabilities and sexual autonomy that can be of use to create better legal instruments and approaches to people with disabilities and their families.

Research Design and Methods

My research is a case study of the Colombian Constitutional Court's line of rulings pertaining the possibility of subjecting people with cognitive disabilities to surgical sterilization procedures, which begins in 2002 with ruling T-850 of 2002 and is maintained to this day. This group of decisions includes 8 rulings: seven of them are cases in which caregivers request the sterilization of their daughters on the basis of a medical diagnosis of cognitive impairment⁴, and the last one, ruling C-131 of 2014, discusses the constitutionality of banning teenagers from governmental-sponsored surgical sterilization programs, included in law 1412 of 2010 by the Colombian Congress. I will on occasion draw from other decisions in order to illustrate some points, but most of the material comes from this main group and the information it contains on the nature of the cases and the families involved. I made the decision to limit my data in this way for two reasons: first, because I could easily gather it from Hungary, and second because it allows me to concentrate on a specific type of discourse. I am not interested so much in the whole phenomenon of surgical sterilization in Colombia for people with cognitive disabilities – that kind of research would require a great amount of time and resources I do not have at present – but on the legal argumentation employed by Courts and judges to justify involuntary sterilization under a climate of compliance with international obligations and human rights. As for methodology, this thesis follows a qualitative analysis of written, legal discourses as they are transmitted by the Court's rulings. I chose to follow this approach because I am interested in the ways in which these discourses shape social relations, systems of representation and categories of knowledge (Tonkiss, 2011, p. 406), specially taking into account that some of these documents do not only include legal

⁴ In Chronological order these rulings are: T-850 of 2002, T-248 of 2003, T-492 of 2006, T-1019 of 2006, T-560a of 2007, T-063 of 2012, and T-740 of 2014.

consideration but also information about the types of families that are looking for access to sterilizations and about the influence of medical discourses in legal theories of disability.

With this in mind, I have organized my thesis into four chapters. The first one will present the main bodies of scholarship that will inform my analysis, mainly feminist and queer theories of disability, and will present some of the specific theories and authors I will draw from in order to answer my research questions. The second chapter will begin the analysis by exploring how normalized notions of individual autonomy and able-bodiedness influence the Court's legal theory on sterilization and cognitive disability, and the third chapter will focus on the intersection between disability, gender and sexuality in the construction of sterilization policies in Colombia. Finally, the last chapter of this thesis will briefly explore some of the alternatives theorists and disability advocates have designed to create better support systems for people with cognitive disabilities and their families, with the aim to show that the current system operating in Colombia and many other countries does not constitute the best option to guarantee the effective protection of sexual and reproductive rights of vulnerable individuals.

CHAPTER 1: THEORETICAL FRAMEWORK

The analysis that I will present in this thesis will primarily draw from the work and theories presented by feminist and queer theories of disability, most of which are currently developed under the field of feminist disability studies. This chapter will first contextualize and outline the most relevant characteristics of this body of scholarship, and then it will address specifically the problems presented by feminist accounts of cognitive/intellectual disability and mental illness. The last section will approach the relationship between liberalism and cognitive disability through the concept of autonomy, which will hopefully set the basis for the analysis of following chapters.

Feminist Disability Studies

In her foundational overview of feminism and disability, *Feminist Disability Studies*, Rosemarie Garland-Thomson frames feminist disability studies as an emerging body of scholarship seeking to destabilize common and dominant assumptions about living with disability (Garland-Thomson, 2005, p. 1557). While feminist engagement with disability can be traced to the growing popularity of disability rights movements in the early 80s, feminist disability studies is particularly interested in furthering the collaboration between feminist theory and disability studies in order to reimagine disability and through it transform our current understanding of gender, race, class, etc. (Garland-Thomson, 2011, p. 16). The intersectional character of these theories has allowed for the continuous development of a wide range of research and insights into the ways in which feminism

and disability can work together (Bê, 2012, p. 363); in that sense rather than an independent and unified body of scholarship, feminist disability studies represents a heterogeneous framework that transcends localized views about disability and women (Bê, 2012, p. 373).

The variety of perspectives found in feminist disability studies does not imply, however, that these works are completely disconnected from each other. On the contrary, scholars mapping the development of this field underscore the existence of common elements such as a social understanding of disability, and the interest to challenge and transform established categories through a complex analysis of the role disability plays in all areas of human life (Bê, 2012; Garland-Thomson, 2005; Hall, 2011). Feminist disability studies also emphasizes the importance of listening to the voices of people with disabilities; several of the most important theorists in this field came to their analyses through their own experiences of disability, and use that understanding in order to enrich the insights of both feminist theory and disability studies (Garland-Thomson, 2005; Kittay, 1999; Morris, 1991). Finally, as a framework of interdisciplinary analysis, feminist disability studies maintains a critical outlook on the theories it draws from; some of its most important critiques are centered on disability studies' over reliance on social explanations of disability, and feminist theory's exclusion of disability as a category of analysis. Since these critiques are central to my analysis of disability and reproduction, I will proceed to explore them in more detail in the following paragraphs.

The interpretation of disability as a social rather than medical phenomenon was developed by disability scholars in order to analyze how modern society fails to account for and accommodate human diversity; this social model of disability claims that a person is made disabled not by their

impairments but by the barriers set in place in their environment and is critical of medical definitions of disability (Barnes & Mercer, 2010, p. 14). In the social model policies tackling disability should then focus on the social marginalization of disabled bodies and on collective mechanisms to reduce exclusion, instead of following a medical view in which disability is an individual tragedy that reduces (or eliminates) a person's quality of life and can only be approached by the medical establishment (Barnes & Mercer, 2010, pp. 22–23). While feminist disability studies recognizes the importance of understanding disability from a social standpoint, it also questions the complete rejection of the medical model and the creation of the impairment/disability binary; treating disability as a purely social phenomenon runs the risk of denying people's experiences of their own bodies (Morris, 1991, pp. 10–11), and privileges a view of “healthy disability”, that is, an idealized subject free from pain and limitations. The radical separation between impairment and disability also overlooks the intricate relationship between people and medical diagnoses, and does not account for those people who advocate for the development of cures and treatments for their conditions (Hall, 2015, p. 3). In addition, I would add that the disability/impairment binary does not respond adequately to the experiences of people with cognitive/intellectual impairments and mental illness. While social integration significantly reduces the difficulties faced by people with these conditions, they are also immersed in complex dynamics of care, and do not conform to those traditional ideas of agency and independence that we usually associate with human dignity and quality of life.

Regarding the relationship between feminist theory and disability, feminist disability studies both recognizes the value of applying feminist analytical tools to the exploration of disability, but also critiques feminist theorists' refusal to engage with disability as a unique category of analysis. One

of the authors who best examines the potential and shortcomings of feminism when it comes to its perception of disability is Jenny Morris; I will follow her main arguments in this section in order to show how disability can inform and add depth to current feminist theories. Jenny Morris' pioneering work on disability and feminism, *Pride against Prejudice*, explores how definitions and perceptions of disability come from non-disabled spaces, and argues in favor of integrating a feminist perspective into disability politics in order to reclaim the value of people's personal experiences in the creation of social change (Morris, 1991, pp. 10–11). That being said, Morris is also very critical of feminist exclusion of disabled women from mainstream feminist theory. For Morris, women and men with disability have very little opportunity within cultural, social and political movements to tell their own story and advocate for their own interests (Morris, 1991, p. 10), and feminist's lack of critical engagement with this area of human experience leads to strong instances of marginalization and even feminist support of selective abortion and eugenic policies against people with disabilities (Morris, 1991, p. 48). Bringing testimonies and experiences of women with disability to light allows Morris to reject philosophical and political standpoints which use disability as criteria to determine if a life is worth living or not; the emphasis placed in liberal feminism on freedom, agency and independence assumes that people make decisions in a complete autonomous fashion, while in reality we are all influenced and impacted by our environment and its prejudices (Morris, 1991, p. 32). Ultimately, Morris employs feminist analytical tools and theories to construct a strong argument in favor of integrating disability into feminist research, not just as an added category but as a transformative concept that brings awareness to the important ways in which race, gender, class, sexuality, age and other identity categories are shaped by stereotypes and prejudices against disabled bodies, and disabled minds.

Feminism, Disability and the Mind

While feminist disability studies posits disability as a category of analysis akin to race, gender, sexuality, class and other centers of oppression, the field has been more interested in analyzing the patterns of meaning assigned to bodies rather than dwelling on specific forms of disability or behaviors (Bê, 2012; Garland-Thomson, 2005; Hall, 2015; Morris, 1991). In *Feminist Disability Studies*, Garland-Thomson emphasizes how the label “disability” is used to imagine a wide range of bodies and traits as defective and inferior, and while she mentions learning disabilities and mental and emotional illnesses among those that are painted with the same brush as physical impairments and chronic illness (Garland-Thomson, 2005, p. 1558), her subsequent review of FDS centers primarily on the work done by or about people with the latter and from those experiences she makes larger generalizations about disability. Jenny Morris on her part justifies this approach by mentioning that while the non-disabled world is concerned with the causes of disability, disabled feminist should focus on the effects and on the common experiences of prejudice and discrimination (Morris, 1991, p. 12). This strategy probably responds to the need to present a somewhat coherent portrayal of disability as a relevant source of stigmatization in order to advocate for its inclusion in mainstream research, but it is important to remember that people with disability are marginalized differently depending on their specific impairments or illnesses, and this fragmentation of social perceptions has important consequences in terms of accessibility, recognition of rights, political participation/advocacy and social inclusion.

In order to respond to the needs of people with cognitive/intellectual impairment and mental illness, feminist disability studies has experienced a gradual shift towards the recognition and study

of these types of disability in the context of feminist theory, philosophy, and societal exclusion. These theories are critical of the ways in which disability studies, feminist philosophy and feminist approaches to disability exploit cognitive/intellectual disabilities and mental illness as argument props in debates such as selective abortions, genetic testing, and animal rights, which rely on and perpetuate denigrating stereotypes of people with disabilities (Carlson, 2001, p. 141). As an example the need for further feminist engagement with cognitive/intellectual impairments, Kim Q. Hall's edited volume, *Feminist Disability Studies* introduces the case of Ashley X⁵ in order to examine how cognitive/intellectual impairments are held under assumptions that link mental disability to eternal childhood and asexuality. Removing Ashley's possibility of experiencing puberty is a manifestation of the idea that the label "disability" automatically replaces all other personal identities, including those of "woman", "mother" and any pertaining sexual identity and orientation; in addition, these procedures raise questions about societal views of female bodily development and menstruation, since it seems that they are perceived as inherently traumatic and negative events (Hall, 2011, p. 4).

Approaching cognitive disability with feminist analytical tools also calls for the reassessment of stereotypes concerning the status of perpetual vulnerability that is characteristic in narratives of mental impairments, and the analysis of the complex dynamics taking place between people with intellectual/cognitive disability and their loved ones/caregivers. Stacy Clifford Simplican proposes a way of theorizing care relationships by developing a "model of complex dependency" which

⁵ This is the case of the "pillow angel", in which the parents of a girl diagnosed with "static encephalopathy" subjected her to a series of procedures in order to prevent her from reaching puberty, under the argument that these interventions would allow Ashley to participate in family life, and would protect her from eventual sexual abuse at the hands of caregivers (Jordan, 2009, p. 32). The larger implications of this case will be explored later in this paper.

recognizes that identities are not static, and that people with cognitive, intellectual or developmental disabilities inhabit spaces of both vulnerability and aggressiveness. (Clifford Simpican, 2015, p. 229). Clifford Simpican comes to this model through the exploration of cases where caregivers are physically abused by their children with autism, which are not prevented or dealt with properly due to the belief that people with disabilities cannot be anything but vulnerable, and that caregivers are obliged to interpret and respond with total effectiveness to the need of their wards (Clifford Simpican, 2015, p. 219). The model of complex dependency considers cognitive/intellectual and developmental disabilities as real, concrete identities that are subjected to particular power dynamics and relationships of dependence and care (Clifford Simpican, 2015, p. 219), and is critical of liberal philosophy and feminist care ethics because they present an unrealistic idea of cognitive abilities: the first idealizes cognitive abilities and devalues the experiences of those who do comply with them, and the second romanticizes care and places people with disabilities in a perpetual position of vulnerability and innocence (Clifford Simpican, 2015, pp. 219–221). The real life applications of this model to the relationship between caregivers and wards that Clifford Simpican presents provide interesting alternatives to dominant models of guardianship and substituted consent, and will be analyzed with more depth in the last chapter of this thesis.

As I mentioned before, an important theme within feminist disability studies is the erasure in mainstream research of the standpoint of people with disability. In the particular context of cognitive impairment and mental illness, this field has produced a number of insightful critiques of feminism and its selective use of these conditions as a literary or historical tools instead of material conditions of actual, real bodies. The instrumentalization of mental illness in feminist

critiques of psychiatry is analyzed with detail in Elizabeth Donaldson's *The Corpus of the Madwoman*, which examines particular feminist tropes relying on unexamined understandings of mental illness and romanticizing madness by treating it as a metaphor for "women's rebellion" (Donaldson, 2011, p. 92). While these critiques of psychiatry are right in pointing out that mental illness diagnoses are gendered, Donaldson claims that they also perpetuate a discourse that erases the lived experiences of people with disability by treating mental illness and cognitive impairment as a symbol instead of a material condition that marks bodies and their realities (Donaldson, 2011, p. 94). The erasure of mental illness and cognitive disability experiences is criticized as well in the work of Licia Carlson, for whom exploring the gendered history of "mental retardation" is vital for future feminist work on cognitive disabilities (Carlson, 2001, p. 124). Carlson denounces the tendency in philosophical discourses to treat cognitive disability as a homogenous group defined by simple, static and unmovable traits, and perceives a risk in these spaces of creating a "Prototype Effect, where one type of 'cognitively disabled' individual (for example, mildly disabled, profoundly disabled) will become the representative of the whole category"⁶ (Carlson, 2001, pp. 140–141). This emphasis on cognitive disability and mental illness as real and heterogeneous conditions also brings into focus an additional and very important aspect of these forms of disability, that is, the link made in political, philosophical and liberal theories (among others) between mental capacity and human worth. The implications of this connection are articulated in mainstream research under the notion of human autonomy, and will be explored in the next section of this chapter.

⁶ The "Prototype Theory" comes from George Lakoff (Carlson, 2001, p. 140)

Cognitive Disability and Autonomy

Autonomy is considered as one of the most important elements of liberal democratic systems and political philosophy (Keller, 1997, p. 154), and it is usually defined as the capacity for self-determination and self-government, and the ability to make personal decisions without pressure from others (Davy, 2015, p. 133). This individualistic notion of autonomy relies on a particular, idealistic vision of the self which is “coherent, bounded, individualized, intentional, the locus of thought, action and belief, the origin of its own actions, the beneficiary of a unique biography” (Rose, 1998, p. 3); in this scenario, individuals are responsible for uncovering and expressing their one true identity, and for acting accordingly in an autonomous and responsible way (Rose 4). Feminist theory has taken this notion of individual autonomy to task for its lack of consideration of the self as relational, and for its unrealistic depiction of individuals as completely free, independent, and bound to others only through voluntary agreements (Keller, 1997, pp. 154–155). Disability studies, on the other hand, has criticized systems and works based on individual autonomy because they deny the personhood of people with disabilities, since they place rationality at the center of human nature and moral worth (Davy, 2015, p. 133). Critiques of autonomy put forward by feminist scholars writing about disability take these arguments and combine them in order to present new models of subjectivity that acknowledge the humanity and experiences of people with cognitive/intellectual disabilities. For the purpose of this research I will follow the work done by Amber Knight and Laura Davy in order to present my own analysis of judicial interpretations of cognitive disability, subjectivity and autonomy. The arguments put forward by these authors bring abstract definitions of autonomy into the field of disability, and

explore the possibilities of reframing traditional understandings of autonomy and human nature in ways that allow for the inclusion of new subjectivities and perceptions of the self.

In *Democratizing Disability*, Amber Knight applies Nancy Fraser's theory of "participatory parity" in order to create a framework that allows people with disabilities to be included in political deliberations without requiring prior assimilation (Knight, 2015, pp. 101–102). Knight considers participation and discussion among citizens as the core of democratic political action, and including the voices of people with disability (both cognitive and physical) would enrich the quality of the debate (Knight, 2015, p. 99). Regarding autonomy, Knight rescues an interpretation of autonomy as the ability for self-reflection, and argues that this a skill that all human beings develop with time. In this sense, it is unfair to disqualify people with cognitive disabilities from political participation based on unexamined assumptions about their capabilities and limitations, and would in turn run the risk of creating a self-fulfilling prophesy: A person who is not expected to develop a skill would not be given the opportunity to learn it, and this failure would then be used against them in order to justify the initial stereotype. For Knight all humans have unexpected potential, and claiming the opposite based on medical diagnosis excludes people from spaces where their contributions could have a strong and lasting impact (Knight, 2015, pp. 109–110).

Laura Davy, on the other hand, employs elements of inclusive design (whose aim is to accept and accommodate human diversity through better design of buildings and public spaces) to explore and critique modern philosophical notions of autonomy (Davy, 2015, p. 132). Davy argues that philosophical environments, much like physical ones, present certain barriers for people with disabilities, mainly due to a narrow perception of personal autonomy which does not take into

account the importance of the environment in human development, and conditions the recognition of rights and moral status to the ability to comply with liberal ideals of rationality, personal responsibility and autonomy (Davy, 2015, p. 135). Davy proposes as alternative a new model of autonomy based on support, advocacy and enablement (Davy, 2015, p. 144); this model sees autonomy as an ever developing attribute of all people (capable of being developed through childhood and adulthood), and understands self-governance as a trait that is enabled through relations of support (Davy, 2015, p. 144). Unlike current philosophical notions of autonomy which deny that the need for support is a universal and inevitable condition, Davis argues in favor of a conception of autonomy as a shared social obligation rather than an individual problem (Davy, 2015, p. 143).

Analyzing autonomy under the light of cognitive/intellectual disability and mental illness allows feminist theory to challenge core beliefs of the self in a different way from other types of disability; as Elizabeth Donaldson states “using a wheelchair does not disrupt the notion of American quite so much as being delusional does” (Donaldson, 2011, p. 105). Disabilities that are located at the level of the mind face more complex social barriers because they defy the notion of subjectivity that sits at the center of western political systems (Donaldson, 2011, p. 105), and demand a new definition of autonomy which takes into account the humanity, dignity and worth of all humans regardless of individual characteristics.

Crip Theory

Like feminist disability studies, Crip Theory is a fairly recent interdisciplinary approach to disability, centered both the ways in which queer theory can inform current theories on disability, and how these two can be combined to enrich analyses of political and cultural systems that have not been previously connected to queerness or to disability (Kafer, 2009, p. 291). Robert McRuer, author of this field's seminal work *Crip Theory: Cultural Signs of Queerness and Disability*, sees in crip theory an opportunity to question how western societies and neoliberal systems rely on particular constructions of heterosexuality and able-bodiedness in order to maintain themselves and sustain its power (McRuer, 2006b, p. 2). Crip theory proponents critique the naturalization of the heterosexuality/homosexuality and the ableism/disabled binaries that creates divisions between "normal" and "abnormal" bodies; as McRuer points out with reference to heterosexuality, "The ongoing subordination of homosexuality to heterosexuality allows for heterosexuality to be institutionalized as "the normal relations of the sexes" while the institutionalization of heterosexuality as the "normal relations of the sexes" allows for homosexuality to be subordinated" (McRuer, 2006b, pp. 6–7). Neither side can be defined or even exist without reference to its opposite; in this sense, a critique of the notion of normalcy is at the core of crip theory analyses, and allows us to interrogate the reasons why we as a society perceive some bodies and identities as desirable, and others as unworthy of moral consideration (Lo'fgren-Ma'rtenson, 2013, p. 414).

One of the most important concepts developed within the field of crip theory, and one I wish to incorporate into my analysis of sterilizations and cognitive disability, is what McRuer refers to as "compulsory able-bodiedness", a term that borrows from Adrienne Rich's work on how heterosexual frameworks depend on lesbian and gay identities to present themselves as the true, natural category of which the latter are merely alternative options or weakened mirror images, in

order to show that these “compulsory heterosexuality” characteristic of modern society is contingent as well on a process of compulsory able-bodiedness that has located abled bodies as the natural and desirable state of being, but that much like it happens with heterosexuality, depends on the strategic visibility of disabled identities in order to reinforce and produce itself (McRuer, 2006a, pp. 89–90). Certainly, as Alison Kafer points out, “Able-bodiedness has been cast as separate from politics, as a universal ideal and a normal way of life, in much the same way as heterosexuality in the 1970s and early 1980s (and, in some contexts, still today)”. (Kafer, 2003, p. 79). The processes and structures imposed by compulsory able-bodiedness not only demand, much like heterosexuality, a constant performance that is never truly perfected, and are also the source of pervasive understandings of disability according to which life satisfaction and happiness are incompatible with disabled existence (McRuer, 2006b, pp. 6–7) or, truth be told, with any subordinated identity.

Much like feminist disability studies, writers approaching disability from a crip theory perspective are also critical of the field’s lack of engagement with cognitive disability and with what might call “able-mindedness”. Lotta Lo’fgren-Ma’rtenson, for example, in her article *Hip to be Crip? About Crip Theory, Sexuality and People with Intellectual Disabilities*, brings crip and queer identification to analyze the process of normalization of certain types of sexuality that do not account for or respond to the sexual expression of people with intellectual disability, and questions crip theory’s tendency to assume that experiences of physical disability are representative of all types of impairments and conditions (Lo’fgren-Ma’rtenson, 2013, p. 415). According to Lo’fgren-Ma’rtenson, crip theory “does not make any reference to intellectual disabilities in his writing. Instead, the theory proceeds from people with physical disabilities, i.e., individuals who have a

voice, who can write about their situation, and organize dissent, and who is often found in the international disability rights movement” (Loˆfgren-Maˆrtenson, 2013, p. 420). Even so, Loˆfgren-Maˆrtenson also highlights the potential of crip theory to question and analyze the social stigma around non-normative sexualities, such as that coming from people with cognitive disabilities, and the attempts to “normalize” these deviant identities as a condition for social inclusion. Margaret Price also writes about the ways in which introducing able-mindedness can enrich feminist disability studies and crip theory, and warns about the danger of simply adding disability to a list of categories present in the first area, or of thinking that crip theories of the body apply without modification to the challenges and characteristics of disabled minds “As Sandra Harding points out in 'Whose Science? Whose Knowledge?' we cannot simply 'add' a category of difference to an existing conceptual scheme if those categories have been defined against each other in the first place. Similarly, if we begin tacking 'and mind' onto our theories of disabled bodies, we will have to think seriously about what that means” (Price, 2015, p. 271).

Feminist and queer theories of disability, as I have briefly explored in this chapter, are opening new paths into examinations of the relationship between disability, gender and sexuality. In the following chapter, I will begin my analysis of judicial theories of sterilization and cognitive disability by bringing the theories I just discussed into the formulation of individual autonomy models and the normalization of particular patterns of thought and action at the core of the Court’s approach to sexual and reproductive rights, which will hopefully provide a good opportunity to show the relevance of the work done in feminist disability studies and crip theory for current cases of exclusion and marginalization of non-normative identities.

CHAPTER 2: STERILIZATION, CONSENT, AND THE MYTH OF INDIVIDUAL AUTONOMY

As I mentioned in the introduction, the first time the Court had the opportunity to address the debate between disability and reproductive rights was in ruling T-850 of 2002 when the mother of Maria Catalina Álvarez reached out to the judges in order to demand the recognition of her right to consent on behalf of her adult daughter (diagnosed with mild mental retardation and epilepsy) to a tubal ligation procedure recommended by her doctors. While in this case the Court denied the petition of the plaintiff and ordered their health care provider and other government agencies to provide adequate resources to Catalina's family in order to find a balance between her disability and her reproductive rights, the way in which the argument was constructed legalized the permanent sterilization of women (and later minors and men) with cognitive disabilities, on the basis of their inability to make autonomous decisions and future incapacity to assume the consequences of their sexuality in a responsible manner. In this chapter, I will analyze the ways in which the Court's approach to disability and reproductive rights relies on the normalization of an idealized autonomous subject and marginalizes already disenfranchised groups. I will argue that although the Court in theory concedes the rights of all people to enjoy and exercise their fundamental rights, in practice the principle of individual autonomy is employed to condition the effective protection of those rights to very high standards of independence and rationality. In addition, this chapter will explore the implications of locating important restrictions to individual

freedoms within the medical sphere, and of granting medical professionals the authority to determine who is and is not entitled to make personal choices over their bodies and their fertility. Finally, this chapter will also explore the consequences of overlooking important causes of oppression such as socioeconomic conditions in legal examinations of disability and reproductive rights, since they exert significant influence on people's ability to access vital social resources and exercise their rights.

Autonomy

Before making a decision regarding Maria Catalina's right to retain her fertility, the Court commissioned the realization of a series of psychiatric, physical and general examinations on Catalina's condition and her family situation. The medical experts in charge confirmed the diagnosis of "mild mental retardation and refractory epilepsy", and concluded that though Catalina showed logical thinking, was not delirious and had benefitted from special education classes (which she had to leave for financial reasons), her condition required partial supervision and would prevent her from understanding the responsibilities attached to parenthood. In interviews Catalina's mother reported supporting her three children with very little income, and having requested the tubal ligation procedure on behalf of her daughter due to a recommendation from her neurosurgeon, who warned her about the high chance of transmission of Catalina's condition to future offspring⁷. Taking these findings into account, the Court began its analysis by formulating two questions that are restated with small variations in later rulings (emphasis added):

⁷ It is also important to note that Catalina expressed in these interviews a desire to be in a romantic relationship, feelings of isolation and loneliness, and a wish to form a family and the future and become a mother. Regarding her

“Does a person have the right, due to her condition of mental and physical weakness, to *receive required medical treatment* when a potential pregnancy would put in serious risk her life and that of the fetus, and *she doesn't have the necessary mental conditions to approach maternity in an autonomous manner*?⁸

“Can the consent of an adult with mild mental retardation be substituted in order to *access a necessary medical treatment* despite her wish to have children in the future, due to medical diagnoses according to which she is not nor will she ever be *aware of the responsibilities attached to motherhood*, and of the grave risks a pregnancy would bring for her health and her life?.⁹

The content, style and language of these questions demonstrates an attempt from the Court to subsume the protection of reproductive rights to an assessment of a woman's capacity to show the “necessary mental conditions to approach maternity in an autonomous manner”, and to portray permanent sterilizations as “necessary medical treatments” even when fertility alone poses no risk to the life of the person in question. Therefore, a critical examination of this strategy not only requires us to understand the elements at the core of the Court's interpretation of individual autonomy but also to explore how this principle is applied to medical consent in Colombian jurisprudence, especially when the patient is in a relationship of constant dependency and support

knowledge of sexual acts and their consequences, Catalina manifested knowing about them, but when pressed she could not tell the interviewers what those consequences were.

⁸ Original in Spanish: “¿Tiene una persona derecho a que, por su condición de debilidad física y mental, se le suministre el tratamiento médico necesario cuando un embarazo supone un riesgo grave para su salud y para el embarazo mismo, y no tiene las condiciones mentales necesarias para afrontar la maternidad de manera autónoma?”

⁹ Original in Spanish: “¿Puede sustituirse el consentimiento de una persona adulta con retraso mental leve para someterla a un tratamiento médico necesario, a pesar de que manifiesta su deseo de tener hijos en un futuro, debido a que, según los dictámenes médicos, no es ni será consciente de las responsabilidades de la maternidad y a que un embarazo implicaría graves riesgos para su salud y para su vida?”

due to a cognitive impairment. Though the Court has made an important number of pronouncements on the content of individual autonomy, I will draw mostly from the eight existing rulings that have been issued so far in the matter of sterilization and disability, since in this study I am not interested in autonomy as a general principle but on its relationship to cognitive disability and gender.

Capacity of Enjoyment

Judicial interpretations of autonomy in Colombia closely follow liberal definitions for which autonomy is the capacity for self-government and the ability to make personal decisions without external pressure (Davy, 2015, p. 135). In ruling T-560A of 2007 (in which the Court discussed the request of sterilization of a 14 year old girl with “congenital metabolic encephalopathy” requested by her mother) the Court brings autonomy into its argumentation as a fundamental democratic principle that recognizes individuals as moral subjects capable of making free and independent choices over their future; in this sense, autonomy is closely linked to the notion of human dignity and to the right of all people to enjoy fundamental rights and personal freedoms. The Court’s understanding of autonomy, however, does not stop with the recognition that all humans are moral individuals entitled to making their own choices. Constitutional jurisprudence in Colombia distinguishes as well between two manifestations of autonomy: that which I mentioned above, and the one that is embodied in the actual capability of acquiring legal obligations towards others. I will examine the second part of this distinction in a later section, but for now I want to concentrate on the connection made by the Court and liberal theory between moral status and the capacity for self-determination.

The moral status of able-bodiedness

The recognition of a person's moral worth (and therefore, the obligation to treat them with respect) has been traditionally tied in liberal tradition to ideals of reason and independence (Davy, 2015, p. 135; Ells, 2001, p. 602). Though modern theorists no longer abide by Kant's view of autonomy as an inherent trait that people could either possess or lack completely (Lindley, 1983), this principle still drives our ideas of what it means to be human, what it takes to build an identity, and what is required of individuals to participate as contributing members of society (Rose, 1998, p. 4). The capacity for self-determination grants access as well to participatory democratic processes since it guarantees the possibility of a legitimate exchange of ideas between free and equal citizens (Knight, 2015, p. 99); in this sense, the capacity to advocate for one's own interests becomes proof of moral worth, and those who cannot do so on the terms dictated by political and social standards end up excluded not just from important spaces of deliberation but also from the "self-governing" group whose interests take precedence over others (Davy, 2015, p. 136). The moral status granted by autonomy, then, becomes more than a formal recognition of a person's humanity and turns into a decisive factor for determining who is entitled to be listened to, and who can be overlooked; only those who are capable of showing independent thought and action, and of making informed and rational decisions over their own lives are believed to be autonomous, and are therefore morally allowed to pursue their own interests and voice their opinions.

The Court's identification of human worth with the capacity for self-determination privileges as well able-minded identities at the expense of disabled ones. As Robert McRuer points out in *Crip*

Theory: Cultural Signs of Queerness and Disability, the subordination of disability to able-bodied identity allows the later to be institutionalized as the normal and desirable state of being while the first is portrayed as inferior, abnormal and abhorrent (McRuer, 2006b, pp. 6–7). McRuer examines the process of normalization of ability with the concept of “compulsory able-bodiedness”, which draws from queer critiques of normalcy in order to show how, much like heterosexuality, able-bodiedness depends for its survival on the constant repetition of social performances aimed at keeping ideals of ability as the norm (even if they will never be achieved in practice) (McRuer, 2006b, pp. 8–9). The definition of autonomy promoted by the Court in its rulings depends for its success on the normalization of cognitive ability as a desired characteristic of the ideal citizen, that is, one who can make autonomous, informed decisions based on a study of available evidence, and is able to exercise their reproductive rights in a responsible manner without external influences. The separation the Court makes between autonomy as a shared principle inherent to human nature and the actual capacity to make choices and exercise personal freedoms is an attempt at justifying the severe restriction of rights without dehumanizing the person, but it fails at doing so because it still sets up disability as a defect, a lack of capacity and a problem to overcome instead of a manifestation of human diversity (This is evident even in the language employed by the Court to refer to cognitive disability: for example, in ruling T-1019 of 2006 people with disabilities are repeatedly referred to as “diminished” (*disminuido*), “handicapped” (*impedido*), and “invalid” (*invalido*); terms that signal a negative view of disability even when the judges claim to abide by definitions of disability as a social phenomenon rather than a physical one). In this context, legalizing surgical sterilizations is not so much a manifestation of the constitutional mandate to give special protection to people with disabilities, but a mechanism to maintain the normalization

of able-mindedness by establishing it as a requirement for the enjoyment and exercise of sexual and reproductive rights.

Individuality

To base the recognition of moral status on the belief that the capacity to make rational choices is inherent to human nature, as the Court does, depends as well on the understanding that autonomy is at its core based on individuality and independence. While this notion has been useful for disability advocacy movements seeking to rescue their identities from a history of repression (Davy, 2015, p. 133), the idea that autonomy is at most an individual pursuit enforces a compulsory regulation of able-bodiedness because it presents the capacity to express preferences without external assistance as a personal achievement, almost as if to depend on others for care and even survival could be up for choice. Indeed, compulsory able-bodiedness often “functions by covering over, with the appearance of choice, a system in which there actually is no choice” (McRuer, 2006b, p. 8); in this case, a system that conditions the recognition of sexual and reproductive rights to the capacity of a person to demonstrate a superior degree of maturity and self-reflexivity (as in ruling C-131 of 2014) masks the fact that many of the disadvantages associated with disability come from a “pervasive cultural system that stigmatizes certain kinds of bodily variation” (Garland-Thomson, 2011, p. 17) and are not contingent on a person’s desire to be “normal” or to belong to socially accepted groups.

The problematic identification of autonomy with individuality has been analyzed as well by feminist writers interested in disability (Back, 2015; Clifford Simplican, 2015; Davy, 2015; Kittay, 1999; Knight, 2015). Laura Davy critiques liberal theory for not acknowledging the fact that human development is informed by social, cultural and historical contingencies, and that human beings grow in constant relation to others (Davy, 2015, p. 138). Even procedural models of autonomy, which condition the recognition of autonomy not on the content of a person's decision but on the process they followed to reach it, do not do justice to the complexity of human relations, even if they admit that caring for others is a valid reason to make a decision (Davy, 2015, p. 139). Eva Feder Kittay, on her part, has an extensive body of work (*Love's Labor* (1999), *The Personal is Political* (2009), *Beyond Autonomy and Paternalism* (2007), and others) where she highlights the inevitability of dependence, that is, the fact that all humans have or will depend on others for the satisfaction of basic needs in circumstances that are not accounted for by the idea that people enter and leave relationships in entirely voluntary terms (Kittay, 1999). Other writers interested in neoliberal depictions of autonomy, such as Nikolas Rose, demonstrate how neoliberal discourses emphasize autonomy as personal responsibility and individuality in order to create an idea of citizenship in which the person engages into self-regulatory practices and take ownership of their own circumstances, even when they have little or no control over them (Rose, 1998, p. 99). The promotion of individuals as free – after being adequately socialized – allows the state to create responsible and productive citizens who internalize state norms and abide by them without the need for government coercion (Davy, 2015, p. 141); in this scenario people with disabilities are then made to take responsibility for their exclusion, as if they had brought societal marginalization on themselves by failing to comply with standards of good, industrious citizenship (Davy, 2015,

pp. 141–142). Going back to the Court’s framing of the legal issues at stake in Catalina’s case¹⁰, we can see that the Court from the beginning places the responsibility for not meeting the required standard of awareness in the person with disability herself. The formulation of the first legal question refers to disability as “mental and physical weakness” and establishes the requirement of showing “necessary mental conditions” to be a responsible parent, which effectively sends the message that people with disabilities are to blame for the restrictions society and the law subject them to.

To take autonomy as an individual principle ignores as well the influence that the environment exerts on a person’s access to adequate resources and the types of barriers they encounter in their daily lives. A significant portion of people with cognitive and psychosocial disabilities report little to no income in Colombia¹¹, and while 7% of people older than 6 did not have access to education in 2005, in the same year the number of people with intellectual and psychosocial disability arose to 53% and 38% respectively (Asdown Colombia et al., 2014, p. 41). As for the Court’s rulings on sterilization and disability, those that include information on the family’s composition and socioeconomic situation¹² show households supported by single parents, with little to no access to special or regular educational institutions, and where the members hold negative ideas of disability. In ruling T-063 of 2012, for example, the plaintiff denied the existence of a cognitive impairment in his daughter but still sought her sterilization under the argument that she was “slow and short of spirit”, and the petitioner of ruling T-492 of 2006 expressed a fear of spreading her daughter’s

¹⁰ ruling T-850 of 2002

¹¹ In 2010 44.6% of people with intellectual disability and 41% of people diagnosed with a psychosocial disability belonged to the lowest income quintile in Colombia (Asdown Colombia et al., 2014, pp. 41–42)

¹² T-850 of 2002, T-492 of 2006, T-1019 of 2006, T-560 of 2007 and T-063 of 2012

condition with future pregnancies, which was supported by the gynecologist she consulted. In the same ruling the mother seeking authorization to sterilize her 26 year old daughter with Down syndrome manifested as one of the driving reasons for soliciting such a procedure her advanced aged (she was 68 years old at the time of the ruling) and the preoccupation of leaving her daughter and grandchildren without any support network after passing away, since they all depended on her low income in order to survive. Catalina's mother expressed a similar sentiment in ruling T-850 of 2002, as well as the plaintiff of ruling T-1019 of 2006 who also saw the procedure of surgical sterilization as a mechanism to ensure that her daughter was not exposed to dangerous situations after her mother had passed away.

The circumstances present in these cases echo the reality of a significant number of Colombian families that welcome surgical sterilization because their environment does not provide the resources to properly address and care for their loved ones¹³; the Court's current stance on disability and autonomy offers, however, a legal framework which does not account for the ways in which class and ability interact and create identities. The rulings I study in this thesis do not incorporate an intersectional approach to the articulation of reproductive rights in the context of disability and idealize individuality in a way that creates the fiction of subjects who develop independently from their environment, excluding people with cognitive disabilities from political participation when the inclusion of their voice would in fact enrich and deepen democratic debate. In this sense I follow Amber Knight's analysis of cognitive disability and democratic inclusion when she argues that a political system that treats people with disability as active citizens would

¹³ See also Linares and Fernandez 2014

need to follow a policy of inclusion without assimilation, that is, it would place the obligation of accommodation on the social and political environment and not on the person seeking participation (Knight, 2015, p. 103). One of the factors to consider in such a scheme is the attempt to reach economic parity - for people with disabilities high unemployment rates and social marginalization are significant factors pushing them towards poverty – since “it is impossible to insulate political processes from structural inequality (...) gender, race, sexuality and class ‘are not neatly cordoned from one another’ and that one dimension of a person’s social status intersects with other aspects of structural power” (Knight, 2015, pp. 102–104). These structural causes of oppression influence families too; no matter what liberal theories of autonomy demand, decisions concerning reproductive rights and disability are not made without external pressure from financial and social circumstances, inherited views or prejudices and entrenched notions of gender and sexuality. Preserving then a vision of autonomy that does not recognize the relational quality of human relations which is present in CC’s rulings leads then to exclusionary and unrealistic policies that do not protect oppressed groups or listen to their opinions.

Capacity of Exercise, Flexibility and Informed Consent

Having explored briefly some of the implications of identifying individual models of autonomy with moral worth, I will now turn to the second expression of this principle, which involves the legal capacity to engage into legal agreements with others. The Court explains this distinction in

ruling C-131 of 2014 (which discussed the legality of banning minors from access to free surgical sterilizations) in the following terms the recognition of moral status based on the ability of every person to be the subject of patrimonial and extra patrimonial rights makes up one's *capacity of enjoyment*, and the ability to obligate oneself to others without external authorization is referred to as *capacity of exercise*. We could understand this in a way that the first category covers the general elements of autonomy as a democratic principle: all humans have dignity from the moment of birth, and the second brings those elements into the realm of actual social relationships, by building a legal framework for the recognition of a person's capacity to manage their own affairs and give valid consent through their expressions of will. Though the Court links the capacity of exercise¹⁴ to the world of business and the management of patrimony, the legal mechanisms created in Colombian law to determine whether a person's consent to act is valid have expanded in such a way as to cover many other scenarios, including the examination of the right to agree to the realization of medical procedures (be they necessary or not). In this sense, analyzing how the Court approaches the notions of capacity and consent in the context of surgical sterilization will allow me to explore the consequences of applying individual understandings of autonomy to the tension between disability and reproductive rights, and how this extends the marginalization of people with cognitive disability in society.

Rules of capacity and Consent

The legal articulation of the capacity of exercise in Colombia comes from the civil code and is expressed in the figure of “legal capacity”¹⁵, which determines the requirements for an expression of will to have legal effects and create obligations towards others. While there is a presumption of capacity for all persons the code also created an exception for those declared partially or completely incapable (art. 1503); in these cases the code bans their acts from creating any legal effects (art. 1504), and creates the figure of interdiction in order to allow a third person (authorized by a judge) to act on behalf of the “incapable” on all acts for which they were declared incapable (civil code, title XXVII). With time interdiction processes began to cover the representation of more acts than those stipulated by the code (that is, civil and commercial acts), and now it currently is perceived by disability advocates as a measure that removes the capacity of people with cognitive, intellectual and developmental disability or mental illness to make any personal decisions without permission from others (Asdown Colombia et al., 2014, p. 79).

Colombian legislation thinks differently. In 2009, Congress approved bill 1306¹⁶, which defines interdiction as one of the mechanisms to reestablish the rights of people with cognitive disabilities

¹⁵ The requirements to be declared legally capable are consigned in the Colombian civil code, art. 1502: “**ARTICULO 1502. REQUISITOS PARA OBLIGARSE.** Para que una persona se obligue a otra por un acto o declaración de voluntad, es necesario: 1o.) que sea legalmente capaz. 2o.) que consienta en dicho acto o declaración y su consentimiento no adolezca de vicio. 3o.) que recaiga sobre un objeto lícito 4o.) que tenga una causa lícita. La capacidad legal de una persona consiste en poderse obligar por sí misma, sin el ministerio o la autorización de otra.” (In english: requirements to acquire obligations: in order to be able to obligate oneself by an act or declaration or will is necessary to 1. Be legally capable, 2. To express consent or declaration of will without any cause for annulment, 3. That it falls on a legitimate object, 4. That it has a legitimate cause.)

¹⁶“which dictates norms for the protection of people with mental disability and establishes a regime of legal representation for the emancipated incapable” Original in Spanish: “por la cual se dictan normas para la protección de las Personas con Discapacidad Mental y se establece el Régimen de la Representación Legal de Incapaces Emancipados”

(art. 25). Unlike the civil code, law 1306 creates the obligation to initiate the process of interdiction for spouses, close relatives, directors of psychiatric hospitals and local ombudsmen, but the same article also states that any person can request the interdiction of a person with cognitive disability (art. 25). Law 1306 also compiles rules of capacity for assessments of disability: people with “absolute mental disability” are “absolutely incapable, and people with “relative mental disability” will only be declared incapable with respect to those acts and businesses they are disqualified from pursuing (art. 15). for this law, a person has an “absolute mental disability” when they “suffer from a profound or severe learning, behavioral or mentally deteriorating condition or pathology”¹⁷ (Art. 16), and in consequence should be under the guardianship of someone who can ensure they have all they need to enjoy a good quality of life (art. 6). While the law states as guiding principles of these measures the importance of respecting the dignity, equality and individual autonomy of people with disability, there is no legal obligation here or in other regulations for judges to interview or gather the testimony of the person object of the measure of interdiction before extending a declaration of incapacity, and in many cases judges only request a psychiatric report from the Medical Forensics Agency in order to determine whether a person should be declared interdicted or not (Asdown Colombia et al., 2014, pp. 60–62).

The rules of capacity regulating the process of interdiction and determinations of total or partial incapacity are related as well to the figure of consent. The ability to agree or reject an offer or an act of any nature is intrinsic to the right of self-determination (Guess, Benson, & Siegel-Causey,

17 Original in Spanish: “Se consideran con discapacidad mental absoluta quienes sufren una affection o patologia severa o profunda de aprendizaje, de comportamiento o de deterioro mental”

2008, p. 77), and it is particularly important in healthcare where it is used to “ground policies and practices about informed choice, the right to refuse treatment (including life sustaining treatment), truth telling, confidentiality, advance directives, and others” (Ells, 2001, p. 599). Carolyn Ells, in her analysis of theories of autonomy and disability in the context of healthcare and dependency relations, highlights how consent is tied to ideas of independence and self-reliance and how the content of those notions depends on the person’s position. Non-disabled healthcare professionals, for example, define independence in the context of self-care activities like being able to dress and move about without assistance, while people with disabilities identify it as the ability to control and make personal decisions including consenting to rehabilitation and medical treatments (Ells, 2001, p. 602).

The importance given by people with disabilities to the recognition of their agency is twice as important in cases of cognitive impairments. As Leslie Salzman points out, we seem ready to accept that there are inexcusable barriers preventing people with physical disabilities from accessing the same services and spaces others do, but not so much when the issue shifts to the barriers faced by people with cognitive disability which involve the possibility of expressing preferences and making choices (Salzman, 2010, p. 285). In relationships with people who require constant assistance and support such as the case with cognitive disabilities, caregivers tend to overlook their ability to voice their opinions and give consent in their interest to look after their physical needs, which reinforces the idea that people with disabilities do not have the capacity to make personal decisions or to even understand their circumstances (Guess et al., 2008, p. 79).

Informed Consent

The Court, in its analysis of reproductive rights and disability, walks the line between a strict interpretation of consent dependent on official declarations of incapacity and a more open view which allows for the possibility of developing autonomous skills with time and resources. The legal theory constructed around these concepts can be described as it was delineated in ruling T-850 of 2002: The Court has a history of respecting the right of a person to make personal choices even when the consequences would be detrimental to their health (such as ruling T-993 of 1993, in which a man petitioned the Court to force her sister to travel to the capital to undergo cancer treatment even though she refused for personal and religious reasons.), as long as there are reasons to suppose that they have the necessary mental abilities to understand the consequences of their actions. In cases where it is not possible to make this assumption (such as instances where the person in question suffers from a cognitive disability or is a minor), the Court considers that the State has an obligation to protect those people with regards to decisions requiring a higher level of autonomy than the one they possess. This protection has two dimensions: on one hand, the State has the duty to ensure that all people reach the necessary level of autonomy in order to make these decisions for themselves – which recognizes the fact that autonomy is not static – and on the other, it is also entitled to take the necessary steps to protect the future ability of that person to express consent in later situations. Ruling T-560A of 2007 (which as I have said before deals with a request to sterilize Kiera Stefanie Hernandez, a 14 year old girl) calls this second dimension “consent oriented towards the future”¹⁸, and it is the reason why parents can legally make decisions for their

18 Original in Spanish: “consentimiento orientado hacia futuro”

children: there is the assumption that once they reach adulthood, they will be able to recognize the generosity and goodness driving the substitution of consent, and will appreciate it.

The notion of “consent oriented towards the future” is also the bridge between interdiction and autonomy in Court rulings, not just in cases with people with disabilities but also for minors. While the declaration of incapacity is not enough to give guardians the power to make such important decisions over the body and the reproductive freedom of their wards, guardians can still request and consent to sterilization procedures on behalf of people declared incapable as long as there is a judicial authorization allowing such a petition combined with the original interdiction process. The possibility of sterilizing a person with cognitive disabilities lies in the medical and judicial estimation of their future capacity to express consent; ruling T-248 of 2003 explains this position in the following terms:

“(...) if, according to the medical state of the art, it can be asserted with a reasonably high degree of certainty that the person will not be able to reach a level of autonomy that allows her to understand and give or withdraw their consent to the realization of a medical procedure (...) if such a circumstance presents itself and, in addition, there is a medical reason to perform the treatment, a judicial order will be enough to authorize it. When there is a lack of capacity to exercise individual autonomy, the medical reason, aimed at safeguarding the life, physical integrity or health of the patient, prevails”¹⁹.

¹⁹ Original in Spanish: “Cosa distinta ocurre cuando, de acuerdo con el estado del arte, se puede sostener con un razonable (alto) grado de certeza que la persona no va a poder alcanzar un nivel tal de autonomía que le permita comprender y dar o no su consentimiento para realizar una intervención quirúrgica. // Si se presenta tal circunstancia y, además, existe una razón médica para realizar el tratamiento, bastará la autorización judicial para que ésta se realice.

This position, translated to cases of sterilization where the realization of such a procedure does not fulfill a rehabilitation purpose, leads the Court to conclude that if there is a medical estimation that the person with disability is not and will never be capable of understanding the consequences of sterilization, it is viable to believe that they will never be capable of understanding the responsibilities of parenthood either, and therefore judges can authorize the procedure as long as both parents (if the person is a minor) or the legal guardian (for adults) provide their consent. The notion of “consent oriented towards the future” then becomes a determining factor for judges to gauge, based on medical reports, whether a person’s future right to exercise their reproductive rights should be protected (and therefore only they can give consent to a sterilization) or if their guardians and the state can make that decision for them.

Consent, in this order of ideas, becomes a pivotal expression of autonomy. While the civil code has a set of criteria in order to determine if a person’s consent should be valid (art. 1502), the fact that the Court treats sterilizations as a “necessary medical treatment” locates the consent necessary to perform the procedure into the field of medical ethics and the concept of informed consent. In ruling T-248 of 2003 (request of sterilization of a teenager diagnosed with “mental retardation, epilepsy and attention deficit disorder (ADD) the Court defines the object of informed consent in the medical sphere as that which creates a pact between the medical professional and the patient,

Ante la inexistencia del ejercicio de la autonomía individual, impera la razón médica, dirigida a salvaguardar la vida, integridad física o salud del paciente.”

with the aim to perform the necessary measures in order to achieve their rehabilitation or recuperation. Consent here then must be *free and informed* (the person must have all the information available and make their decision without any prejudice or coercion that might limit their autonomous decision), *qualified* (the person must provide proof of their consent for future verification of the authenticity of their choice), and *constant* (medical information must be provided along the entirety of the clinical treatment, also during the post-operative phase). Therefore, in order for the state and a judge to recognize the right of a person to provide informed consent to a surgical sterilization procedure there must be reasonable evidence to suggest that they can meet these four requirements not just now, but in the future. In turn, the existence of these elements is sufficient proof as well of the capacity of that person to understand the consequences and responsibilities attached to giving birth and raising a child, so their absence in someone can reasonably lead a guardian, a doctor or a judge to believe that the person in question should not be allowed to make a choice in that regard. The figure of interdiction would here allow a person to pose as guardian, and the same medical report used as evidence for the incapacity could in all likelihood be employed to authorize a sterilization, even if the Court establishes stronger limitations in these cases (Asdown Colombia et al., 2014, pp. 61–62).

Asking people with cognitive disabilities as young as 14 to prove beyond reasonable doubt that even if they cannot do so at present they will be able to rationally analyze, assess and make truly informed decisions on their reproductive freedom without external pressure is to subject them to a higher standard of rationality and independence than the rest of us (Davy, 2015, p. 135). In addition, the Court's rulings are proof enough of the danger of leaving this decision to health care providers that do not know the law, medical professionals who hold backward and detrimental

views about disability, and caregivers who are under constant external pressure to care for a loved one without the knowledge or resources to do so. In none of the 7 rulings in which the Court has encountered petitions by guardians to sterilize a person with cognitive disabilities have the judges allowed so, and on the contrary, the facts of these cases as well as rulings from lower judges have evidenced concerning state of affairs for these people. In ruling 560A of 2007, 5 years after the creation of the mandate to obtain additional judicial authorization to perform sterilizations of people with cognitive disability, the plaintiff provided documents sent to her by the general Ombudsman's office, the Colombian Agency for Family Welfare and other governmental institutions in which they stated that there is no legal disposition requiring judicial authorization to perform a surgical sterilization in people with disabilities besides the one declaring their incapacity or, for minors, parental consent. In ruling T-063 of 2012 the plaintiff's health care provider authorized the realization of a sterilization on an adult woman on request of her father without even asking for a judicial declaration of incapacity, and in ruling T-1019 of 2006 the request of sterilization was denied by the petitioner's health care provider not because they lacked judicial authorization, but because the girl in question did not have the required age to undergo the procedure (she was 16 at the time).

Prejudices concerning cognitive disability are also a factor that drives requests for sterilization. In most of these rulings parents and caregiver are informed of the need to sterilize their daughters by their doctors, due to the eventual probability of transmission of the mother's condition (as in T-850 of 2002) or casual assessments of present and future lack of autonomy (like in ruling T-560A of 2007); in addition, the medical experts commissioned by the Court in these cases have all recommended surgical sterilization procedures even for women with mild mental retardation who

could very well improve their skills with appropriate treatment and education (with the exception of ruling T-063 of 2012)²⁰. The official sanction of these attitudes by the Court and by Colombian legislation furthers the notion that people with cognitive disabilities are “defective” individuals who cannot regulate themselves are cannot be productive members of society (Davy, 2015, p. 142), as well as expresses a normalizing view of able-bodiedness and able-mindedness by which the visibility of “deviants” is allowed in social circles only to emphasize the flexibility and superiority of able-minded identities (McRuer, 2006b, pp. 18–19).

Finally, I want to make a brief reflection about one aspect associated with medical understandings of disability that is overlooked by the Court and its sterilization policies, and it is related to the international obligations acquired by the Colombian government through the ratification of international conventions that seek to recognize the moral worth of all humans, especially those who have been object of exclusion in the past. One of the most important instruments in the field of disability is the UN Convention on the Rights of Persons with Disabilities, ratified by Colombia in 2011, and it includes the express obligation to respect the right of all people with disabilities (including children) to “retain their fertility on an equal basis with others” (art. 23). This article responds to a history of sexual and reproductive repression of people with disabilities created by racial hygiene methods and eugenic initiatives; sterilization was one of the most popular manifestations of negative eugenic measures, a term that covers all attempts to “improve” the quality of the human race by preventing the “unfit” from reproducing (Moore, 2004, p. 266). Eugenics advocates fed on growing anxieties around racial degeneration and combined them with

²⁰ Rulings T-850 of 2002, T-492 of 2006, T-1019 of 2006, T-560 of 2007, C-131 of 2014, T-740 of 2014

theories of hereditarianism in order to make a case for the prevention of “overproduction of degenerates” through segregation and sterilization (Stepan, 1985, p. 114). In this context, it is disingenuous for the Court or any other official agency to create and validate sterilization policies for people with disabilities without taking into account the fact that governments and institutions have abused this procedure to rid themselves of “inferior” sectors of the population, not just people with disabilities but those coming from the wrong class and race, like the cases of forced sterilization in Peru and those against Roma women in Eastern Europe (Stoyanova, 2013) and female inmates in U.S. prisons (Johnson, 2013) In addition, while I could not find any report in Colombia linking the state to systematic programs of forced sterilizations, medical professionals in Colombia hold eugenic views about people with cognitive disabilities to such an extent as to consider them a social threat. One doctor told researchers from a Colombian university as much, concluding “I don’t know if it’s going to sound a bit Nazi, but some people should not reproduce” (Escuela de Medicina y Ciencias de la Salud, 2014, p. 6).²¹ These views translate to actual judicial rulings and determinations of absolute incapacity by judges that take medical reports as the only necessary evidence in cases of interdiction and sterilizations, many seeing their role and the whole interdiction process as a simple “legal” recognition of the medical assessment, and not as a measure to guarantee the protection of human rights (Asdown Colombia et al., 2014, p. 62).

Applying informed consent standards to the recognition of reproductive rights the Court is reinforcing societal values that create boundaries between those who have access to the

²¹ Original in Spanish: “yo no se si suene un poco nazi, pero reproducirse no me parece”

management of their fertility and their sexuality and those who are found wanting; autonomy then, regardless of speeches about the universality of moral status and formal recognitions of the right of all persons to self-determination, is still seen as an individual trait under complete control of the person and isolated from external circumstances. As Ells explains, “autonomy cannot be authority over and control of *all* aspects of the self, for the relational components of the self make much of the self-situation relationship a shared contingency” (Ells, 2001, p. 612). A true recognition of autonomy as relational would lead the Court to pay closer attention to the ways in which humans develop with relation to others and are never truly independent; here I also follow Davy when she proposes a model of autonomy (which I will examine in the last chapter of this thesis) that asks society not to look for the absence of factors when assessing someone’s autonomy, but to the presence of advantages such as social support and self-confidence, among others. As she points out, even the seemingly self-made entrepreneur was once a child in need of parental support, a student who received assistance from teachers, and friend or a husband who got love a support from his personal circle, and therefore none of us have a claim to true, independent success (Davy, 2015, p. 144). Garland-Thomson wisely reminds us all as well that disability is one of the true universal human experiences, and society needs to account for it and find ways to accept it as one more expression of human diversity instead of creating barriers that marginalize (Garland-Thomson, 2011, p. 17). Sterilizing individuals because they do not meet the requirements to be thought of as “normal” is not one of those ways.

CHAPTER 3: SEXUALITY AND DISABILITY IN THE CONSTRUCTION OF STERILIZATION POLICIES

In the last chapter I examined how employing individual models of autonomy to justify restrictions to reproductive rights on the basis of a disability reinforces existing boundaries between societal perceptions of “normal” and “abnormal” identities, and prevents formal recognitions of moral status from transforming into actual claims to sexual and reproductive rights. Judicial and legislative support of surgical sterilization in Colombia, however, rely on more than traditional understandings of autonomy and human development in order to excuse the reproductive marginalization of people with cognitive disabilities; while rationality and independence are at the core of the Court’s legal position on this matter, judges have also incorporated feminist and pro-choice arguments into their argumentation in such a way as to allow them to present the involuntary sterilization of women with cognitive (or as ruling C-131/14 says, “severe and profound”) disabilities as a protective measure compatible with human rights standards. In this chapter I want to analyze how disability intersects with gender and sexuality in the elaboration of legal justifications of sterilization in cases of cognitive impairment. Colombia’s current approach to cognitive disability struggles to combine traditional understandings of autonomy and moral worth with international obligations acquired by the State pertaining the effective recognition and protection of sexual and reproductive rights of people with disabilities; in this sense, I believe that the Court takes advantage of feminist and human rights discourses in order to claim compliance with international law without actually modifying national approaches to disability and gender.

Though the Colombian legal system currently accepts (and promotes) the sterilization of men and women with cognitive disabilities, before Congress passed bill 1412/12 the procedures approved by judicial precedent were only those intended to prevent pregnancies in women with cognitive impairments. Indeed, with the exception of ruling C-131/14 – in which the matter under discussion was the constitutionality of legalizing surgical sterilizations for minors – to this day the Court has only encountered cases presented by parents seeking the realization of this procedure on their daughters, under allegations of personal safety (rape and STD prevention)²², fear of transmission of the mother's condition to the fetus or malformations derived from medication²³, financial duress²⁴, and inability of the woman to assume or live up to the responsibilities of motherhood²⁵, among others. In consequence, in addition to developing an approach to cognitive disability based on individual interpretations of autonomy the Court. constructed as well an analysis of the extent to which the state's commitment to the protection of disabled women's rights includes an obligation to relieve them from the burden imposed by their sexuality and their fertility (since they are in no position to manage them).

The formulation of this inquiry and the conclusions presented by the judges in their decisions are significant insofar as they portray a vision of motherhood and sexuality as privileges of

²² T-1019/06, T-560A/07

²³ T-850/02, T-248/03, T-492/06, T-1019/06

²⁴ T-492/06

²⁵ T-850/02, T-560A/07, T-063/12, T-740/14

autonomous, able-minded individuals, and simultaneously exclude from and tie women with cognitive disabilities to stereotypical gender expectations. In order to explore the details and implications of this position I will draw mostly from the considerations found in ruling T-248 of 2003, because it is there that the Court. articulates for the first time its take on sterilization as both a manifestation of women's rights and as a social duty. I will also complement my analysis with two additional rulings: T-988 of 2007 and T-946 of 2008, in which the Court. examined the legality of authorizing and performing abortions in women with cognitive disabilities. I expect these rulings to provide a more comprehensive understanding of the consequences of conditioning reproductive rights to individual models of autonomy both for disability and for feminist advocacy and theory.

The problems of liberal feminism in analysis of cognitive disability

Ruling T-248/03 compiles the Court's examination of a petition to order the sterilization of a teenage girl diagnosed with "mental retardation, epilepsy and attention deficit disorder (ADD)²⁶". While the decision follows for the most part the guidelines established the previous year in ruling T-850/02 pertaining disability and autonomy, the Court here incorporates a new layer into its argument by fashioning surgical sterilization into a measure of protection of women's agency; the matter at hand is then presented in the formulation of this questions: "Can a person who cannot (and never could) understand or assume the consequences derived from a pregnancy, *be forced* to endure it? (...) Is the protection of people in a state of manifest weakness limited to prevent them

²⁶ Original in Spanish: "epilepsia, retardo mental y trastorno del déficit de la atención".

from becoming victims of abuse and crime, or does it extend to *preventing the possible consequences* of said crimes?”²⁷ The answer provided by the Court to these problems can be summed up in three main arguments: First, to subject women with “severe mental problems” to have a child when they lack the capacity to form a family or to decide on the number of children they choose to have is disproportionate, and in these scenario all pregnancies should be seen as forced. Second, the protection of female autonomy and the right to make personal decisions over our own bodies demands from society and the state the recognition that it is no possible to assume a universal female desire for motherhood, especially when they do not have any real capacity to decide. Doing so would be to accept a pseudo-autonomy based on biological determinism, and to degrade the person to a mere being with the physical capacity to reproduce. In consequence, the third argument claims, judges have no option in these cases but to authorize surgical sterilizations on women when circumstances (such as personal safety) mandate the effective protection of a person in state of manifest weakness and the genuine respect for women’s rights.

To frame the sterilization of women with cognitive disabilities as a necessary mechanism to prevent women from being reduced to their reproductive capacity is both a paternalistic measure, and an attempt to employ feminist defenses of female agency to legitimize severe restrictions of personal freedom. This strategy is problematic for a number of reasons, but first I will concentrate on the reasons why the Court was able to call on feminist theory in order to coat its ableist notion of reproductive and sexual rights with the appearance of a deep concern for women’s agency and

²⁷ (italics not in the original) Original in Spanish: ¿puede una persona, que no puede (ni podrá) comprender las consecuencias derivadas de un embarazo o asumir las consecuencias del mismo, ser forzada a soportarlo? (...) ¿La protección de las personas en debilidad manifiesta se limita a evitar que sean víctimas de abusos y hechos punibles, o se extiende a prevenir las posibles consecuencias de tales hechos punibles?”

autonomy. While feminist, queer and disability theorists have already begun to explore the ways in which analysis of disability can enrich feminist philosophy (Bê, 2012; Garland-Thomson, 2005; Hall, 2015; Kafer, 2003; Kittay, 1999), the lack of engagement of mainstream feminism with the challenges women with disabilities face affects more than theoretical debates and can even be used as a tool of marginalization. This is why institutions like the Court can avail themselves of arguments put forward by feminist theory with regards to women's agency and sexual and reproductive freedom in order to justify the limitations of those same rights; the same propositions that have been used to improve the social and political conditions of women are susceptible then to increase the level of inequality between them, and to normalize able-bodied privilege under claims of autonomy and protection.

As I mentioned in previous chapters, feminist disability studies scholars have underscored the relationship between patriarchal notions of gender and disability (Bê, 2012; Donaldson, 2011; Garland-Thomson, 2005) Garland-Thomson analyzes western thought's association of femaleness and disability: both have been deemed inferior and are referred to in terms of inferiority and lacking (Garland-Thomson, 2011, p. 18). Female embodiment and heavily feminized jobs are perceived as handicaps in society, and bodies marked by particular races and genders (such as the case of the Hottentot Venus²⁸) are pathologized and represented as incomplete, deficient, dependent and vulnerable. As Garland-Thomson remarks, "gender and race oftentimes are performances on disability" (Garland-Thomson, 2011, pp. 18–19). And yet, as Ana Be points out, feminism's

²⁸ The "Hottentot Venus" refers to the case of Saartje Bartman, a South African woman who was subjected in the 19th century to scientific examinations by Georges Cuvier (considered the "father of modern biology") and whose anatomy was portrayed by mainstream science as proof of the inferiority and degeneracy both of African races and of the female gender (Fausto-Sterling, n.d., p. 20).

approach to disability has been one marked by common prejudices and misconceptions. In its quest to present itself as a desirable political identity, feminist movements distanced themselves from disabled bodies, minds and experiences in order to show how, unlike the “truly” disabled, women did not conform to “stereotypes of women being dependent, passive and needy” (Bê, 2012, p. 364); Even when feminism has directly addressed conditions such as mental illness it has usually done so as a symbol for “women’s rebellion” and a strategy to prove how transgressive femininity and feminism are, instead of treating it as the lived experience of millions of women and a real condition marking bodies and their realities in a wide variety of ways (Donaldson, 2011, pp. 93–95). For Sharon Lam and W. Carol Cleigh, “the move by feminists to separate women from the devalued group of “defectives” without challenging the hierarchy that produces it served to make disability central to feminism as a negative trope (Lamp & Cleigh, 2011, p. 176).

The interest of feminist theory to rescue the category of “woman” from a historically subordinated position has, then, led to a tendency to neglect the experiences of people with disabilities and the influence of gender, race and class into constructions of able-bodiedness and able-mindedness (Taylor, 2015, pp. 183–184). As Alyson Kafer points out, it is very difficult to find feminist authors outside of feminist disability studies who are willing to interrogate their able-bodied privilege in the same way that they do for other types of identity categories (Kafer, 2003, p. 77); In this sense, it should not come as a surprise that institutions like the Court can rely on feminist keywords and theories to promote the exclusion of women with cognitive disabilities, since they were not taken into account in their development in the first place. Recent cases in Latin America, such as the

Peruvian “National Population Program” of the 90’s²⁹ show how negative tropes about cognitive disability, indigenous ethnicity and poverty can be combined together in massive sterilization programs allegedly designed to reduce poverty by safeguarding women’s sexual and reproductive rights (Boesten, 2007, p. 6). Indeed, doctors and official agents participating in this program expressed beliefs linking poverty and disability; language barriers between government officials and indigenous women living in rural areas were taken as sign of irrationality and a lack of mental capacity to understand basic birth control methods, and stereotypes about the “promiscuity” of Andean women were perceived as well as sign of mental inferiority and deficiency (Boesten, 2007, p. 15). While Colombia does not manifest an express interest in starting a similar campaign, it has availed itself from a similar rhetoric in order to increase the popularity of sterilization as a desirable method of birth control for all women, everywhere, with no further thought on how preconceived notions of disability impact other categories such as gender, race and class. Insofar as it has remained mostly silent on these matters, feminist theory needs to take ownership of its ableist privilege and rescue its theories from the grasp of governments and institutions counting on discourses of sexual and reproductive freedom and poverty alleviation to promote population control policies, especially because they rely on the naturalization of able-bodiedness and on the

²⁹ During the decade of the 90’s, Peruvian president Alberto Fujimori developed a family planning program called “National Population Program” which attempted to alleviate poverty in the country by, among other strategies, reducing the growth of Peruvian population, promoting a decrease of fertility in Peruvian women, and guaranteeing “the freedom of choice and the reproductive rights of persons” (Boesten, 2007, p. 6). Between 1993 and 1999 the program (which counted with international funding and support from the US agency for International Development (USAID) and other agencies) had sterilized approximately 314000 people in Peru, a goal achieved through systematic psychological and economical pressure against the poorer sectors of the population and indigenous communities (Málaga, 2013, p. 521). Most of the “sexual and reproductive health” campaigns offered food subsidies and access to governmental programs in exchange for consent to sterilizations, and some even resorted to threats and deception in order to meet official quotas (Puertas, 2002).

silence of feminist circles to justify the eradication of disenfranchised groups under claims of progressiveness and “responsible” parenthood.

Sexual Stereotypes and Disability

The strategic appropriation of feminist discourses to legitimize sterilization policies for women with cognitive disabilities is not only evidence of the need for a true engagement between feminist theory and disability studies, but also of the ableist beliefs at the core of the Colombian state’s understanding of sexuality and reproduction. As I previously stated, ruling T-248/03 framed the legal debate around sterilization and cognitive disability not as a problem of ableism and reproductive freedom but as an inquiry into the state’s duty to prevent the consequences of crimes and “forced pregnancies”, which presumes that all sexual contact with a woman with cognitive disabilities – and, as I will explore later, all pregnancies – are constitutive of sexual assault. This position establishes able-bodiedness as the boundary for the recognition of a person’s sexuality, and echoes damaging stereotypes about the sexuality of people with disability which have led in the past to inhumane, restricting measures against them. In this section I will explore some of those misconceptions, as well as the consequences of believing that sterilization are effective tools against to prevent sexual abuse.

As a sign of inferiority, cognitive disability has been the object of both discriminatory and contradictory stereotypes regarding sexuality (Block, 2000; Carlson, 2001; Rohleder, 2010; Taylor Gomez, 2012). Miriam Taylor Gomez describes both extremes: people with cognitive impairments are either perceived as asexual, with the corresponding lack of any sexual feeling, or hypersexual,

which is represented in improper behavior and differs depending on the gender: women are believed to be promiscuous, and men to engage in public sexual displays (Taylor Gomez, 2012, p. 238). These extreme notions of sexuality are associated with historical prejudices surrounding cognitive disability that linked mental illness with immorality and racial degeneration, and which saw sexual “deviance” (out-of wedlock pregnancies and promiscuity for example) as a symptom of mental retardation (Carlson, 2001, p. 126). For Pamela Block the sexuality of women with cognitive disabilities simultaneously inhabits two sexual identities; that of the innocent, sexually vulnerable child, and the socially threatening, promiscuous woman, and both cases demand constant management and social control (Block, 2000, p. 239). The dual character of cognitive disability is supported as well by the common idea that people labeled under this category are not run by rationality but by instinct, and in consequence they act more like animals than humans (Sandland, 2013, p. 85). Hall argues that this is a consequence of western notions of the body as a separate entity (and a hindrance) from the mind, which in turn informs contemporary ideas of people with disabilities as “out of control”, since they do not conform to the seamless ideal proposed by gender roles, sex characteristics, and ableism (Hall, 2015).

The characterization of people with cognitive disabilities as sexual deviants (either by a lack or an excess of desire) has a great influence in the way caregivers understand and respond to their ward’s sexual development and expression, and on the articulation of gender roles. Pamela Block’s study of cognitive impairment and sexuality in Brazil is useful to illuminate the relationship between these elements: in a society with strong religious and conservative values (which I believe is also the case in Colombia), women with cognitive disabilities are held to strict gender values in all of their interactions except those related to their sexuality, which tends to be forbidden even in

relation to heterosexual activities (Block, 2002, p. 16). In this context, parents tend to transfer their own anxieties of sexuality on their daughters, often resorting to “extreme actions to prevent their adult children from having sexual lives”, such as isolation and beatings (Block, 2002, p. 24). Block’s findings in Brazil are supported by other studies, such as Poul Rohleder’s (2010) analysis of educator’s ambivalent attitude towards providing sexual education for people with learning disabilities. Due to the contradictory construction of the sexuality of people with cognitive disabilities, sexual education is seen as both unnecessary – since they are supposed to be asexual – and dangerous – because it might encourage an already excessive sexual expression (Rohleder, 2010, p. 167). When sexual education is provided, parents and educators emphasize the inappropriateness of sexual behavior outside of a heterosexual, monogamous relationship, and construct sexuality as dangerous in order to discourage curiosity about sex (Sandland, 2013, p. 177).

The Court’s rulings I examine in this thesis illustrate both sides of ableist representations of women’s sexuality and cognitive disability, and the way they affect caregiver’s approaches to sterilization and reproductive rights. Ruling T-063 of 2012, for example, discusses the case of a man requesting the sterilization of her 21 year old daughter, on grounds on her perceived “slowness and shortness of spirit”³⁰. On his petition Aureliano³¹ argues that her daughter, Ursula, “escapes from home and cannot measure the consequences, since people or unscrupulous men can abuse

³⁰ Original in Spanish: “lenta y corta de espíritu”

³¹ Given the nature of the case, the Court decided to give false names to the people involved

her, taking advantage of her situation, and transmit all kinds of STDs”³² Psychologist interviews with Aureliano reported a complicated relationship between him and Ursula; not only did he deny her daughter’s condition (moderate mental retardation) but he also blamed her for her seemingly “reckless” sexual behavior and for her apparent ungratefulness towards him. Sterilization in this case was presented as a mechanism to prevent the consequences of Ursula’s sexual behavior; in addition, he assumed that an eventual pregnancy would necessarily be a negative event in his daughter’s life, since one of his arguments for requesting the sterilization procedure was to prevent Ursula from “suffering”³³. The depiction of the men in Ursula’s life is also quite telling: All men who come in contact with her are “unscrupulous” and will take advantage of her “slowness”, which effectively delegitimizes any sexual contact Ursula might engage in.

A similar sentiment is shared by the plaintiff of ruling T-560A of 2007 which examines the possibility to sterilize a 14 year old girl (Kiera Stefanie Hernandez) with moderate mental retardation. Kiera’s mother expressed a great deal of concern over her daughter’s physical development, in her own words

“I go out with her and she gets lots of looks because she’s very pretty: tall (aprox. 157 cms) and is very well developed, she doesn’t look at the boys or older men that stare at her. About two years ago I was with Kiara, I took her out to play with a skateboard and then the phone rang so I had to go back to answer, and when I went back out the neighbors told me

³² Original in Spanish: “además de que se escapa de la casa y no sabe medir las consecuencias, ya que personas u hombres inescrupulosos pueden abusar, aprovechándose de su situación y le pueden transmitir cualquier enfermedad de transmisión sexual”

³³ Original in Spanish: “No quiero que la niña sufra”

that a man that lives around and likes vice called and she went over to where he was and he was touching her when the neighbors came out (...) she is so pretty and looks normal at first sight and then after a while it begins to be noticeable, doctor this is her ID, in the photo she looks like a normal person”³⁴.

This testimony highlights another common stereotype associated with cognitive disability: the idea that people with cognitive impairments are willfully manipulative and will take advantage of their situation to deceive others. In a Colombian study in which judges and public officials were questioned about their understanding of cognitive disability and the usefulness of legal guardianship, a representative from the Ministry of Education expressed his belief that interdiction was necessary in these cases to ensure that people with cognitive disability could not “take advantage of their condition”³⁵ (Asdown Colombia et al., 2014, p. 54). While not as pervasive as it once was, there continues to be an association between women with cognitive disabilities and “immoral” sexual behavior; judges in the U.S. for example have accepted defenses from accused sexual abusers in which victims with cognitive disabilities are portrayed as hypersexual and a threat to men, since their impairment is not readily apparent to sexual partners (Block, 2000, p. 248). The perception of women with cognitive disabilities as both innocent and threatening creates complex situations that lead to heavy social control and policing, and buttress the belief that they

³⁴ Original in Spanish: “Yo salgo con ella y la miran mucho porque es muy bonita, es alta mide aproximadamente 1.57 de estatura y está muy formada, ella no mira a los muchachos ni a los viejos que la miran. Hace por ahí por dos años yo estaba con Kiara, yo la saqué a jugar con una patineta y en esas me sonó el teléfono, yo entré a contestar y cuando salí las vecinas me dijeron que un señor vecino de la cuadra que inclusive es vicioso la llamó y ella arrimó y él la estaba manoseando cuando salieran las vecinas, él se entró (...). [Ella] es tan bonita que a simple vista se le ve normal y ya después de repararla mucho si se le puede notar, doctora esta es la tarjeta de identidad de ella, donde en la foto se ve como normal”

³⁵ Original in Spanish: “Evitar que se puedan aprovechar de su situación”

are not capable of making personal decisions or exercising their sexual and reproductive rights. It is under this environment that the Court formulated the legal debate around sterilization as one of protection against rape; if sexual encounters with people with cognitive disabilities are not legitimate either because they are not capable of sexual desires or because they have no control over their excessive sexual impulses (both alternatives imply an absolute lack of autonomy), then in consequence pregnancies would necessarily need to be perceived as forced or at the very least unwanted.

Violability of disabled bodies

Constructing pregnancies as forced when the mother has a cognitive disability is an argument the Court makes not just in its approach to disability but also in cases of abortion. In Colombia abortion is illegal in all cases with three exceptions (formulated by the Court in ruling C-355 of 2006): “(i) when the continuation of the pregnancy constitutes a danger for the life or health of the woman, and is certified by a doctor, (ii) when there is a grave malformation of the embryo, to the extent to make its life inviable, (certified by a doctor), and (iii) when the pregnancy is result of a conduct, properly reported to the authorities, constitutive of non-consensual sexual abuse or artificial insemination”³⁶. The first two cases are fairly straightforward, but the third has particular implications for women with cognitive disabilities and the exercise of their reproductive rights.

³⁶ Original in Spanish: “(i) Cuando la continuación del embarazo constituya peligro para la vida o la salud de la mujer, certificada por un médico; (ii) Cuando exista grave malformación del feto que haga inviable su vida, certificada por un médico; y, (iii) Cuando el embarazo sea el resultado de una conducta, debidamente denunciada, constitutiva de acceso carnal o acto sexual sin consentimiento, abusivo o de inseminación artificial o transferencia de óvulo fecundado no consentidas.”

The Court has developed its interpretation of abortion and disability in two rulings so far: T-988 of 2007 and T-946 of 2008; both center around cases where women with a variety of cognitive impairments were discovered pregnant by their families due to the presentation of different symptoms, and at least in the first the report of sexual abuse to the authorities included a suspect, close to the woman and her family. In both cases medical professionals refused to perform or authorize the interruption of the pregnancy, either because the woman's parents were not legal guardians of their daughter and there is no certainty of her legal incapacity or her inability to express consent (T-988/07), or because of the doctor's conscientious objection (T-946/08). There are many interesting aspects to analyze in these cases, but for the purpose of this thesis I want to focus on their presentation of the relationship between pregnancy, disability and gender.

In short, the Court considers that abortion is an expression of women's rights and their agency over their bodies, except when the woman, "whose disability is a notorious event – in this case, physical, psychic and sensory that prevent her from expressing her free and direct consent – was victim of sexual abuse"³⁷. For these cases, demanding any document besides the report of sexual abuse by the woman's parents (or caregivers) would be disproportionate; given the fact that the women in question "were not just victim of sexual abuse, but it is also evident to all that the circumstance of pregnancy with the physical, psychic and sensory limitations that characterize their disability contribute to make her situation worse and to considerably deteriorate their quality

³⁷ Original in Spanish: "una joven cuya discapacidad es un hecho notorio – en este caso, limitaciones físicas, psíquicas y sensoriales que le impiden manifestar su consentimiento de manera libre y directa - quien fue víctima de abuso carnal sin consentimiento y abusivo."

of life”³⁸. Judicial declarations of interdiction (and therefore judicial proof of a woman’s legal incapacity) or psychological exams to corroborate the woman’s lack of consent or desire to terminate the pregnancy are part of the requirements that the Court considers to be excessive in cases of abortion and cognitive disability, particularly taking into account the fact that for the judges pregnancies make it impossible for women with cognitive disabilities to live free of pain and humiliations. In consequence, the parents of adults or children with cognitive disabilities can request and authorize their daughter’s abortions after reporting to the authorities the commission of a sexual abuse.

While it is true that in some extreme cases cognitive and developmental disabilities are not compatible with pregnancies due to the risk such an event would pose for a woman’s life or health (especially if medication is involved), the Court’s permission to caregivers to take control of women’s pregnancies when they have been diagnosed with cognitive disabilities is characteristic of a society in which bodies marked as disabled are perceived as “profoundly ‘other’” (Carlson, 2001, p. 141). Sexuality and reproduction are located at a very special angle concerning the normalization of able-bodiedness and the denaturalization of disability; as Foucault says, “sexuality, being an eminently corporeal mode of behavior, is a matter for individualizing disciplinary controls that take the form of permanent surveillance (...) but because it also has procreative effects sexuality is also inscribed, takes effect, in broad biological processes that concern not the bodies of individuals but the element, the multiple unity of the population”

³⁸ Original in Spanish: En el caso analizado, la joven no solo fue víctima de violación sino que resultaba a todas luces evidente que la circunstancia del embarazo con las limitaciones físicas, psíquicas y sensoriales que caracterizan su discapacidad, contribuían a empeorar su situación y a desmejorar de modo considerable su calidad de vida.

(Foucault, 1997, p. 251). Strict control is then enacted on disabled bodies, in part through the imposition of sexual scripts “regarding the when, where, how, with whom and why” of sexual expressions and reproduction (Lo’fgren-Ma’rtenson, 2013, p. 420) which ensure (or attempt to at the very least) their compliance with “normal” expressions of sexuality. If we assume that reproduction is as much a duty as a social right, and that Foucault’s analysis of the dual dimension of sexuality was correct, then it follows that states and institutions will regulate their access according to pre-established standards of able-bodiedness, as the Court does in the rulings I cover here.

Another consequence of the process of “othering” that is representative of western societies is the belief that people with cognitive disabilities do not experience trauma – especially sexual trauma – with the same intensity as everybody else. In Pamela Block’s study of cognitive disabilities in Brazil, medical professionals and care workers expressed a similar sentiment: ““When I interviewed them, some professionals expressed the belief that cognitive disability serves to shield individuals from the trauma of sexual victimization (“the memory will fade...”)” (Block, 2002, p. 18). This idea leads families, caregivers and medical professionals to consider the physical integrity of people with cognitive disabilities to a lesser degree than those of others, and has opened the door to a number of invasive practices against them like medical experimentation, exclusion from democratic participation, and eugenic practices (Davy, 2015, p. 137). In the cases I examine here and in the context of Colombia’s sterilization policies, parents (especially if they come from a low socioeconomic background) combine beliefs around the “low” impact of sexual assault on women with cognitive disabilities with the practical impossibility to protect them at all times, and deal with the perceived inevitability of rape by requesting sterilizations for their daughters. After

all, and as the mother of a girl with cognitive disabilities expressed to a Colombian journalist, “if the health care system performs one of those procedures on her (daughter) and her life doesn’t run any risks, then that would take a weight off my shoulders. If I don’t have enough to take care of one person, then I’d have even less for two”³⁹ (Linares Gomez & Fernandez, 2014). The Court has attempted to distance itself from such assumptions by framing sterilizations and abortions on women with cognitive disabilities as a problem of autonomy and protection of reproductive rights, but the trope of surgical contraception as a tool for sexual abuse prevention is very much at the core of its understanding of these issues, which is evidenced by the fact that like I explained, in ruling T-248 of 2003 the Court mentioned that concerns about “personal safety” were reasonable enough for a judge to grant sterilization requests.

“Personal Safety” and the danger of puberty

As I mentioned before, the Court defined sterilizations in ruling T-238 of 2003 as a mechanism to prevent the consequences of sexual abuse against people with cognitive disabilities. While it the Court made it clear in ruling T-063 of 2012 that its theory of sterilizations of people with cognitive disabilities should not be perceived as a mechanism to prevent sexual abuse, manipulation or STDs⁴⁰, the formulation of the legal debate around this procedure and the reasoning behind it

³⁹ Original in Spanish “Si el sistema de salud le hace un procedimiento de estos, sin que su vida corra peligro, me quitaría una carga de encima. Si no tengo para mantener a una persona, mucho menos a dos”

⁴⁰ In this ruling, the Court stated that sterilizations are “a surgical alternative that would only avoid unwanted pregnancies, and leaves uncovered any type of protection with respect to acts of sexual abuse, STDs or manipulation by external parties” Original in Spanish: “Así mismo, porque se trata de una alternativa quirúrgica que tan solo evitaría embarazos no deseados, quedando al descubierto cualquier tipo de protección respecto de actos de abuso sexual, enfermedades de transmisión sexual o manipulación por terceros inescrupulosos, como lo advirtió la misma institución.”

established a direct relationship between sterilizations and sexual abuse. This stance is so problematic that at least one judge has presented a dissenting opinion with the argument that allowing sterilizations under the conditions established by the Court is a violation of people's human rights. In 2014 Judge Luis Ernesto Vargas Silva expressed his disagreement with the decision achieved in ruling C-131 of that year, which as I have said before, declared the legality of sterilizing minors as young as 14 with "severe and profound" disabilities. Judge Vargas agreed with the overall decision (which ruled that nondisabled minors needed to wait until turning 18 before being eligible for surgical sterilizations), but considered that allowing the sterilization of teenagers with cognitive disabilities not only perpetuates negative stereotypes about disability, but is also incompatible with the social model of disability the Court aligns with and violates the effective recognition of children's sexual and reproductive rights.

For Judge Vargas, "to approach disability from the point of view of extreme cases can generate violations of fundamental rights, without even considering less burdensome alternatives or taking into account the constitutional level of the rights in question". To construct theories around disability around "extreme cases", as Judge Vargas states, is also an example of a tendency in philosophical and political discourses to treat people with cognitive disabilities, and disability in general, as a homogenous group (Carlson, 2001, pp. 140–141). Licia Carlson brings Lakoff's concept of "prototype effect" to explain one of problems with theorizing about disability from the point of view of cases located at both ends of the spectrum: in these theories and policies, one type of "cognitively disabled" individual becomes representative of the whole category (Carlson, 2001, p. 141). If we define disability and impairment as static conditions with fixed characteristics, we are denying the possibility of development that is so easily recognized to non-disabled individuals

and run the risk of accepting policies that, as the Court does with sterilization and reproduction, restrict personal freedoms and rights using as example cases that do not account for the majority of individual experiences of disability.

Judge Vargas also expressed his disagreement with the idea that women with cognitive disabilities should bear the burden of their vulnerability by being sterilized for “personal safety” reasons. In his words, “sexual abuse victims cannot, under any circumstance, assume this unjustifiable burden or endure a restriction in their fundamental rights in order to prevent forms of violence and abuse, but instead {The State} should implement mechanisms that facilitate the prevention, report and punishment of these crimes”⁴¹. Several studies have shown that surgical contraception provide no shelter against sexual violence against vulnerable people (Cook & Dickens, 2000; Stefánsdóttir, 2014). This critique is echoed by Colombian reports in which they highlight this argument as one of the main reasons parents are advised by doctors to apply for surgical contraception (Committee on the Elimination of Discrimination against Women., 2013, pp. 28–29). Since pregnancy is an undisputable sign of sexual activity it is hard for attackers to deny the abuse and in this sense, the case could be made for arguing that sterilization actually aids the attacker by masking the evidence of rape, as Block has found in Brazilian hospitals in which sterilization is seen by some care workers as means to cover abuse “if a patient became pregnant, it was the responsibility of the hospital. If the patient was sterilized, then sex and rape were rendered invisible” (Block, 2002, p. 14).

⁴¹ Original in Spanish: “Las víctimas de violencia sexual, no deben en ningún caso, asumir esta carga injustificada, ni sus derechos fundamentales deben ser restringidos, pensando en prevenir formas de violencia y abuso, sino que se debe propender por implementar mecanismos que faciliten la prevención, la denuncia y el castigo de tales flagelos.”

That being said, societal anxiety towards sexual deviance, reproduction and disability goes further nowadays than sterilization and abortion policies, and are related to the tendency to think of people with cognitive disabilities as children that is so prevalent in western culture, and to the association between “appropriate” sexual expressions and compulsory rules about able-mindedness. These cultural fears now take advantage of medical advances and understandings of disability (that render life with illnesses or impairments unworthy of satisfaction and happiness (Hall, 2015, p. 6) to expand sexual repression policies on disabled minds and bodies onto the field medical experimentation. The case of Ashley X has been received with such a degree of controversy precisely because of this reason: it has been presented by the doctors involved and by Ashley’s family as a groundbreaking effort to improve her ability to participate in social activities and as a measure against sexual abuse (Wilfond, Miller, Korfiatis, Diekema, & Goering, 2010, p. 27). To summarize, Ashley’s case came to the attention of public opinion in 2006 when her doctors published a paper to a scientific journal reporting on the procedures they performed on Ashley after consultation with her parents. Ashley was subjected to what is now called as the “Ashley treatment”, which includes “surgically removing her uterus, appendix, and breast buds, followed by thirty months of estrogen therapy to stop her body’s physical growth. Although she will exhibit normal signs of aging, Ashley will not grow beyond a height of four feet, five inches nor weigh more than seventy-five pounds” (Jordan, 2009, pp. 20–21). Ashley’s parents were worried about the increased difficulties that come with a greater height and weight, but also expressed concern about the perceived physical trauma of menstruation and breast development, and an additional concern that larger breasts “could “sexualize” Ashley towards her caregiver, especially when they are touched while she is being moved or handled” (Jordan, 2009, p. 32).

Ashley's case evidence two things: the first is the societal need to render disabled bodies as inconvenient as possible (and the tendency to burden them with the task of overcoming the barriers placed on them) and the second is the fear families and caregivers experience towards female sexual development, and the ways in which compulsory able-bodiedness influences disabled bodies to the extent to not just restrict but also to eliminate the possibility of sexual expression on "abnormal" bodies by, as doctors did with Ashley, keeping her within a child's body. There is a pervasive belief that women's organs and the female body itself were made only for reproductive purposes; in studies conducted in Taiwan, for example, women with cognitive were subjected to sterilizations and hysterectomies by their families and husbands because they and their doctors tend to see the uterus as a useless organs if it cannot not be used for childbearing (Chou & Lu, 2011, p. 67). While it is true that the Court in Colombia has not given permission for such intrusive measures in women's lives on the basis of disabilities, I consider as well that its approach to sterilizations and abortions, as well as its understanding of sexuality and able-mindedness open the door to the realization of medical experimentation on disabled bodies to, as the Court itself has said, "protect" them from the consequences of abuse.

Judicial legitimization of sterilizations and abortions of women with cognitive disabilities in Colombia respond to a myriad of assumptions about disability, sexuality and autonomy. Judges, medical professionals and caregivers rely on these tropes to establish the parameters of interaction between them and people with cognitive disabilities, and the current legal frameworks of guardianship and interdiction do not adequately respond to the needs of either party, nor do they shield disenfranchised groups from the risk of abuse, or protect the exercise of their sexual or

reproductive rights. The next chapter will analyze the alternatives theorists and some governments have formulated to create better environments for people with cognitive disabilities, taking into account the critiques I have presented here so far.

CHAPTER 4: EXPLORING ALTERNATIVES: SUPPORTED DECISION- MAKING MODELS

Before concluding this thesis, I want to very briefly present some of the ways in which national legislations are adapting to new paradigms concerning cognitive disability and autonomy. In contrast to traditional mechanisms of legal guardianship, these systems are based on an approach called “supported decision-making”, that rather than restricting decision-making rights of people with cognitive disabilities, provides them with support to understand the relevant information needed to make personal choices, assess possible implications, and communicate their decisions to others (Salzman, 2010, p. 306). Supported decision-making models are contemplated on art. 12, numeral 4 of the UN Convention on the Rights of Persons with Disabilities, that states:

“State Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.”

For the UN, supported decision-making models apply even for people with disabilities in relationships of permanent dependency; in these cases, the “support person” (that is, the interpreter or caregiver) should attempt to aid the person with a disability to exercise their legal capacity as much as possible. As for the role of supporter, it can take the form of a single trusted individual or be fulfilled by a network, and it can be performed occasionally or be more permanent (Office of the Public Advocate - South Australia, 2011, p. 6). It should be noted as well that there is no single supported decision-making model, but those who have been developed so far share some characteristics: (i) the person’s legal right to make decisions is not compromised by the appointment of an assistant, (ii) the person enters this relationship on their own accord and can terminate it at any point, (iii) the person must actively participate in decision-making processes in accordance to the appointed powers – the assistant might be held responsible if its proven that the consultation did not take place (iv) decisions made within these framework are legally binding and (v) if a surrogate decision maker is appointed (under special circumstances), this function has to be time-limited and can only be extended with judicial consent. (Salzman, 2010, p. 306).

Supported decision-making models are relatively new and they are just beginning to be developed and adapted in several countries, for the purpose of this thesis I only want to present some of them in order to show how they construct new relationships between cognitive disabilities and their environment. The first model I want to talk about is Stacy Clifford Simplican’s PATH (Planning Alternative Tomorrows with Hope); though she did not create it, she has been trained as a PATH facilitator and to that extent she can provide useful insights into its characteristics and functioning (Clifford Simplican, 2015, p. 227). The second model is proposed by the Office of the Public

Advocate of South Australia in collaboration with other institutions, and is articulated in a “Supported Decision Making Agreement” which covers decisions made in the areas of accommodation, lifestyle and health care, among others (Office of the Public Advocate - South Australia, 2011, p. 18). Finally, I will present the recommendations made by the Mental Disability Advocacy Center to policy makers and legislators in order to develop supported decision-making models that respond to the characteristics of each country.

PATH (Planning Alternative Tomorrows with Hope)

Stacy Clifford Simplican presents this model of supported decision-making as an example of systems that can account for the full complexity of people with cognitive disabilities and the relationships they establish with their caregivers (Clifford Simplican, 2015, p. 227). She defines it as a “person-centered, ‘team-facilitated graphic planning process’ in which two facilitators guide a group of people to develop a comprehensive life plan with and for a person with a disability” (Clifford Simplican, 2015, p. 227). For Clifford Simplican, this model achieves two aims: it tries to interpret the needs and desires of the person with cognitive disabilities with transparency, and also leaves spaces open for tension that is natural in relationships of care. In this way, it dispels romanticized visions of disability as perpetual vulnerability, and creates a dialogue between both parties in which the needs of all are recognized and respected (Clifford Simplican, 2015, pp. 227–228). The graphic nature of this model allows people with cognitive disabilities to express themselves without being forced to submit to normative linguistic ideals, and creates commitments from all participants that are open to modification and further discussion. (Clifford Simplican, 2015, p. 228).

I include this model in my thesis because it creates an alternative to guardianship that recognizes the needs of people with cognitive disabilities, but also responds to the needs and desires of their families and loved ones. Relationships of care are susceptible to cases of abuse, not just against those marked as disabled but also against the people caring for them. Parents have been known to murder their children due to misguided beliefs of the unbearable “suffering” that comes with disabled lives⁴² (Kafer, 2003, p. 80), and they have also been victims of abuse and even murder, as it happened to Trudy Steuernagel in 2009, who was found unconscious and later died as a result of a beating from her son, who was diagnosed with autism (Clifford Simpican, 2015, p. 218). PATH recognizes the complex nature of these relationships and does not propose easy solutions, but a climate in which all parties are recognized as equals and problems are worked through with everyone’s input. While it is true that national strategies might not be able to prove the same level of depth to all families or relationships, I consider that this model has an interesting approach to cognitive disability and autonomy, in the sense that it sees these concepts from a social perspective and combats the isolation that is characteristics of guardianship models. In contrast, the second model takes a more formal approach to decision-making processes, with the creation of legally-binding (if it has the acknowledgment of the state) agreements between people with cognitive disabilities and their supporters. The following section will outline its main characteristics.

Supported Decision Making Agreements

⁴² Kafer mentions here the case of Tracy Latimer, whose father killed her in 1993 because he could not endure her permanent state of “suffering” (Kafer 80)

The specific formulation of this supported decision making model is taken from the proposal from the Office of the Public Advocate in South Australia (OPASA). It attempts to realize the model of support contemplated in the UN Convention on the Rights of Persons with Disabilities, and it marks a distinction between its scope and spaces of mentorship, therapy, advocacy and other informal means of support for people with cognitive with disabilities (Office of the Public Advocate - South Australia, 2011, p. 18). Other areas that are excluded from the agreement are decisions pertaining voting preferences, religion and marriage, which can be discussed between the supported person and the supporter, but can in no way be object to formal agreements (Office of the Public Advocate - South Australia, 2011, p. 18). The decisions covered by the agreement, then, are mostly limited to activities related with accommodation (where to live, with whom, etc.), lifestyle (work, education, recreation), and health (consideration of treatment options) (Office of the Public Advocate - South Australia, 2011, p. 18). As for the specific obligations contained in the agreement, OPASA includes the following: the supported person will have to be able to: “express a wish to receive support, form a trusting relationship with another person, indicate which decisions they might need support for, indicate who they wish to receive support from for which decision, express a which to end support if that time comes, and to be aware that they are making the final decision and not their supporter” (Office of the Public Advocate - South Australia, 2011, p. 21). The supporter, in turn, will agree to, among other commitments, “respect the individual decision making style of the supported person, undertake research to assist the person make this decision, to communicate the person’s decision, and if necessary advocate for the implementation of the person’s wishes” (Office of the Public Advocate - South Australia, 2011, pp. 21–22).

OPASA's presentation of supported decision-making agreements is very detailed and complex, but for the purpose of this thesis it is enough to mention that it expressly acknowledges that decision-making processes are a skill that can be developed with time and education through a "capacity building" approach. (Office of the Public Advocate - South Australia, 2011, p. 33)

. Ideally, these agreements would gradually increment the supported person's capacity to make personal choices without assistance, but the important aspect is that the relationships established here are not contingent on proving a specific degree of rationality or physical independence. I consider this aspect to be very important for national constructions of policies based on support, because unlike guardianship, it does not condition the recognition of rights or the human worth of people to static declarations of independence, but on the contrary it highlights the value of education and the potential of all humans to benefit from inclusive spaces (Office of the Public Advocate - South Australia, 2011, p. 33). Though OPASA does not dwell on the practical application of these agreements for the exercise of sexual and reproductive rights, I think that the parameters set by this organization can apply to these spaces with careful adaptations depending on each case. It is here that I move to the Mental Disability Advocacy Center's (MDAC) recommendations to governments seeking to develop supported decision-making models, since they could also apply to national implementations of OPASA's agreements.

MDAC'S Recommendations

The set of recommendation included in this section is part of the MDAC's "Legal Capacity in Europe" report, and it is here because I consider it a useful set of guidelines to modify Colombia's official stance on capacity and disability, especially when it comes to the respect of sexual and

reproductive rights. In this section I will briefly discuss some of them. The first recommendation is to “involve persons with intellectual disabilities and persons with psycho-social disabilities and their representative organizations in any law and policy reform process” (Mental Disability Advocacy Center, 2013, p. 29). This recommendation is particularly important in Colombia, since it directly addresses the importance of taking into account the voices of people with cognitive disabilities in the creation of policies that affect their fundamental rights. Assuming, as the Court does, that the inability to express oneself in socially approved ways grants others the right to determine what is best for us, effectively excludes disenfranchised people from deliberation processes that impact their lives. In this context the MDAC’s recommendation is vital to even begin to think about modifications on social policies and disability, and it is the foundations for supported decision-making models.

Another recommendation mentioned by the MDAC is to “provide all relevant public officials, civil servants, judges, social workers and other stakeholders with training in consultation and cooperation with persons with disabilities and their representative organizations, at the national, regional and local levels, on the human rights model of disability and recognition of the legal capacity of persons with disabilities and on mechanisms of supported decision-making” (Mental Disability Advocacy Center, 2013, p. 29). The rulings object of this thesis showed that no policy recognizing the sexual and reproductive rights of people with cognitive disabilities can ever be successful if the officials and professionals appointed to enforce it are still operating under damaging assumptions concerning these group. From judges to caregivers to medical professionals and health care providers, all relevant parties need to be trained on the specific needs of people

with cognitive disabilities; otherwise we will end up with contradictory information and the subordination of people's rights to personal prejudices and misinformation.

The final recommendation I will mention here is the one pertaining “collect comprehensive data on individuals subject to legal capacity restrictions and supports (including those subjected to guardianship and trusteeship while these systems exist)” ” (Mental Disability Advocacy Center, 2013, p. 29). Colombian studies on legal capacity and sterilization have remarked on the lack of information gathered by national institutions on the incidence of surgical sterilizations, which prevents researchers and policy makers from assessing the consequences or impact of decisions concerning the exercise of sexual and reproductive rights of people with cognitive disabilities (Asdown Colombia et al., 2014, p. 55). Changes in sterilization policies in Colombia need to first account for the impact of these procedures on the population, or at least to show that such severe limitations on the personal freedoms of vulnerable groups are closely monitored given the likelihood of abuse. Along with the need to take into account the opinions of people with cognitive disabilities and their advocates, and the importance of educating the public and the state in the characteristics of disability, the availability of useful data is essential to propose and implement new frameworks of political and social participation for people with cognitive disabilities in Colombia and other countries. The models and ideas I presented in this chapter are fairly new and require more study and deliberation, but take a step in the right direction to increase the participation of people with disabilities in all spheres and social structures, and in that sense I consider their analysis very important to examinations of disability, gender, sexuality and other identity categories.

CONCLUSION

In the course of this thesis I have explored the relationship between legal theories on sterilization and stereotypes concerning disability, gender and sexuality. I set out to show how judicial analyses of surgical sterilizations on people with cognitive disabilities are informed by pervasive tropes characterizing bodies and minds marked as disabled as inferior, deviant, aberrant and abnormal. Colombia's official stance on the possibility to sterilize people with cognitive disabilities (and in particular, to sterilize women) is a manifestation of the power of able-bodied regulations in modern society, so much so that severe restrictions of sexual and reproductive rights are seen as appropriate and even desirable protection mechanisms of social control. By analyzing the discursive strategy employed in the rulings object of this project, I also wanted to start a discussion on the ways in which feminist theories are strategically employed by governments and neoliberal systems in order to coat with the appearance of legitimacy regulations that in practice deny the moral status and worth of disenfranchised groups, and called for an increased level of engagement of feminist analysis both with disability as an important system of representation, and with cognitive disability due to the particular challenges it presents to mainstream notions of gender and sexuality.

This thesis also illustrated some of the reasons why individual models of autonomy, so influential in the creation and implementation of figures such as guardianship, interdiction, informed consent and legal capacity, cannot be analyzed in isolation, without taking other aspects such as class and sexuality into the discussion. Colombia's case has shown that parents who request sterilizations for their children and the adults under their care are under an enormous amount of external pressure, such as the lack of economic resources to provide adequate conditions and proper

education for them. In this context, respecting a person's sexual and reproductive rights might mean having to deal with an unexpected pregnancy and all the obligations it entails; the absence of mechanisms of support for these families does not make their situation any easier, and in that sense sterilizations could provide at least one source of respite. In addition, medical models of disability and the perceived authority of medical professionals play an important part as well in the general reception of sterilizations policies for cognitive disabilities. Doctors hold on to and propagate radical ideas of capacity and autonomy based on medical diagnosis that do not leave much room for the relational aspect of autonomy and human development, and it seems that the Court, despite its discourse about human rights and protection of women's integrity is still very much influenced by outdated notions of what a person with cognitive disabilities is capable of doing. To modify this paradigm, it is necessary to be aware of the underlying social constructions giving support to these models, and the ways in which they naturalize themselves by creating a category of "others", against which they can compare themselves and feel superior.

My brief exposition of current alternatives to traditional guardianship models attempted to show how the discussion I want to start with this case analysis can be relevant outside of Colombia; though international conventions are beginning to switch their approach to disability, many states still see cognitive impairments and mental illness as a problem that needs to be eradicated, solved or overlooked, and in the meantime the human rights of thousands of people are being violated by societies that perceived them as subhuman. Guardianship models are not designed to address properly neither the needs of people with cognitive disabilities nor the needs of their caregivers, and in that sense it is vital to develop new approaches that take into account the social character of the negative tropes around disability that we seem to take as natural and unchangeable.

I hope this thesis was able to contribute to a growing dialogue between disability studies and feminist theory. While it is true that it is only an analysis of a limited number of rulings and there are still a great deal of factors to consider, like assessing the impact of sterilization policies in Colombia, and their relationship to other systems of representation such as race and religion, I believe that my findings can help to illustrate the problem with applying able-bodied ideas of the self to situations that do not conform to such standards. More important than that, I hope that it evidences the need to account for and consider disability in feminist analyses of social and political institutions and situations.

REFERENCES

- Asdown Colombia, fundaMental Colombia, Brujula, Profamilia, Universidad de los Andes, & Páais. (2014). *Capacidad Juridica, Derechos Sexuales y Derechos Reproductivos de las Mujeres con Discapacidad Intelectual y con Discapacidad Psicosocial en Colombia* (p. 97). Open Society Foundations.
- Back, L. (2015). Private Dependence, Public Personhood: Rethinking “Nested Obligations.” *Hypatia*, 30(1), 115–131.
- Barnes, C., & Mercer, G. (2010). *Exploring Disability* (2nd ed.). Cambridge: Polity Press.
- Bê, A. (2012). Feminism and Disability: A Cartography of Multiplicity. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge Handbook of Disability Studies* (pp. 363–375). London: Routledge.
- Block, P. (2000). Sexuality, Fertility, and Danger: Twentieth-Century Images of Women with Cognitive Disabilities. *Sexuality and Disability*, 18(4), 239–254.
- Block, P. (2002). Sexuality, Parenthood, and Cognitive Disability in Brazil, 20(1), 7–28.
- Boesten, J. (2007). Free Choice or Poverty Alleviation? Population Politics in Peru under Alberto Fujimori. *European Review of Latin American and Caribbean Studies*, (82), 3–20.
- Carlson, L. (2001). Cognitive Ableism and Disability Studies: Feminist Reflections on the History of Mental Retardation. *Hypatia*, 16(4), 124–146.
- Centro de Derechos Reproductivos. (2014, March 18). Organizaciones de varios países rechazan decisión de la Corte Constitucional colombiana que avala esterilización de menores con discapacidad sin su consentimiento. Retrieved from

<http://www.reproductiverights.org/es/comunicados-de-prensa/Organizaciones-de-varios-paises-rechazan-decision-de-la-Corte-Constitucional-colombiana%20>

- Chou, Y.-C., & Lu, Z.-Y. (2011). Deciding about sterilisation: perspectives from women with an intellectual disability and their families in Taiwan. *Journal of Intellectual Disability Research*, 55(1), 63–74.
- Clifford Simpican, S. (2015). Care, Disability, and Violence: Theorizing Complex Dependency in Eva Kittay and Judith Butler. *Hypatia*, 30(1), 218–233.
- Committee on the Elimination of Discrimination against Women. (2013). *De La Esterilización Forzada a La Psiquiatría Forzada*. (No. 56). Geneva.
- Cook, R. J., & Dickens, B. M. (2000). Voluntary and involuntary sterilization: denials and abuses of rights. *International Journal of Gynecology & Obstetrics*, 68, 61–67.
- Davy, L. (2015). Philosophical Inclusive Design: Intellectual Disability and the Limits of Individual Autonomy in Mora and Political Theory. *Hypatia*, 30(1), 132–148.
- Donaldson, E. J. (2011). Revisiting the Corpus of the Madwoman: Further Notes toward a Feminist Disability Studies Theory of Mental Illness. In K. Q. Hall (Ed.), *Feminist Disability Studies* (pp. 91–113). Indiana University Press.
- Ells, C. (2001). Lessons About Autonomy from the Experience of Disability. *Social Theory and Practice*, 27(4), 599–615.
- Escuela de Medicina y Ciencias de la Salud. (2014). Derechos Sexuales y Reproductivos de las Personas con discapacidad intelectual: ¿Está Preparada Nuestra Sociedad? *Universidad de Ciencia Y Desarrollo - Programa de Divulgacion Cientifica*, 9(1), 1–11.
- Fausto-Sterling, A. (n.d.). Gender, Race, and Nation: The Comparative Anatomy of “Hottentot” Women in Europe, 1815-1817. In J. Terry & J. Urla (Eds.), *Deviant Bodies: Critical*

Perspectives on Difference in Science and Popular Culture (pp. 19–48). Indiana University Press.

Foucault, M. (1997). *Society Must be Defended*. New York: Picador.

Garland-Thomson, R. (2005). Feminist Disability Studies. *Signs*, 30(2), 1557–1587.

Garland-Thomson, R. (2011). Integrating Disability, Transforming Feminist Theory. In K. Q. Hall (Ed.), *Feminist Disability Studies* (pp. 13–47). Bloomington and Indianapolis: Indiana University Press.

Guess, D., Benson, H. A., & Siegel-Causey, E. (2008). Concepts and Issues Related to Choice Making and Autonomy Among Persons with Severe Disabilities. *Research & Practice for Persons with Severe Disabilities*, 33(1-2), 75–81.

Hall, K. Q. (2011). Reimagining Disability and Gender Through Feminist Disability Studies: An Introduction. In Kim Q. Hall (Ed.), *Feminist Disability Studies* (pp. 1–10). Bloomington and Indianapolis: Indiana University Press.

Hall, K. Q. (2015). New Conversations in Feminist Disability Studies: Feminism, Philosophy, and Borders. *Hypatia*, 30(1), 1–12.

Johnson, C. G. (2013). *Female inmates sterilized in California prisons without approval*. Center for Investigative Reporting. Retrieved from <http://cironline.org/reports/female-inmates-sterilized-california-prisons-without-approval-4917>

Jordan, J. W. (2009). Reshaping the “Pillow Angel”: Plastic Bodies and the Rhetoric of Normal Surgical Solutions. *Quarterly Journal of Speech*, 95(1), 20–42.

Kafer, A. (2003). Compulsory Bodies: Reflections on Heterosexuality and Able-bodiedness. *Journal of Women’s History*, 15(3), 77–89.

Kafer, A. (2009). What ’ s Crip About Queer Theory Now? *Sex Roles*, 60, 291–294.

- Keller, J. (1997). Autonomy, Relationality, and Feminist Ethics. *Hypatia*, 12(2), 152–164.
- Kittay, E. F. (1999). *Love's Labor: Essays on Women, Equality, and Dependency*. Psychology Press.
- Knight, A. (2015). Democratizing Disability: Achieving Inclusion (without Assimilation) through “Participatory Parity.” *Hypatia*, 30(1), 97–114.
- Lamp, S., & Cleigh, C. (2011). A Heritage of Ableist Rhetoric in American Feminism from the Eugenics Period. In *Feminist Disability Studies* (pp. 175–189). Bloomington and Indianapolis: Indiana University Press.
- Linares Gomez, A., & Fernandez, C. F. (2014, March 18). Polémica por esterilización de niños con déficit mental. *El Tiempo*. Retrieved from <http://www.eltiempo.com/archivo/documento/CMS-13675515>
- Lindley, R. (1983). *Autonomy*. London: Macmillan.
- Lo'fgren-Ma'rtenson, L. (2013). “Hip to be Crip?” About Crip Theory, Sexuality and People with Intellectual Disabilities. *Sexuality and Disability*, 31(4), 413–424.
- Málaga, G. (2013). Las Esterilizaciones Forzadas, Los Derechos Reproductivos y el Consentimiento Informado. *Revista Peruana de Medicina Experimental Y Salud Pública*, 30(3), 521–522.
- McRuer, R. (2006a). Compulsory Able-Bodiedness and Queer/Disabled Existence. In L. J. Davis (Ed.), *The Disability Studies Reader* (2nd ed., pp. 88–99).
- McRuer, R. (2006b). *Crip Theory: Cultural Signs of Queerness and Disability*. New York: New York University Press.
- Mental Disability Advocacy Center. (2013). *Legal Capacity in Europe: A Call to Action to Governments and to the EU* (p. 82). Retrieved from

<http://www.mdac.info/en/resources/legal-capacity-europe-call-action-governments-and-eu>

- Moore, J. (2004). The Fortunes of Eugenics. In D. Brunton (Ed.), *Medicine Transformed: Health, Disease and Society in Europe 1800-1930* (pp. 266–297). Manchester University Press.
- Morris, J. (1991). *Pride Against Prejudice: Transforming Attitudes to Disability: A Personal Politics of Disability*. London: The Women's Press.
- Office of the Public Advocate - South Australia. (2011). *Developing a Model of Practice for Supported Decision Making* (p. 36). Collinswood: Office of the Public Advocate - South Australia.
- Price, M. (2015). The Bodymind Problem and the Possibilities of Pain, *30*(1), 268–283.
- Puertas, L. (2002, July 25). Fujimori ordenó la esterilización forzosa de 200.000 mujeres indígenas en Perú. *El País*. Retrieved from http://elpais.com/diario/2002/07/25/internacional/1027548004_850215.html
- Rohleder, P. (2010). Educators' ambivalence and managing anxiety in providing sex education for people with learning disabilities. *Psychodynamic Practice*, *16*(2), 165–182.
- Rose, N. (1998). *Inventing Ourselves*. Cambridge: Cambridge University Press.
- Salzman, L. (2010). Guardianship for Persons with Mental Illness - A Legal and Appropriate Alternative? *Saint Louis University Journal of Health Law & Policy*, *4*, 279–330.
- Sandland, R. (2013). Concubitu Prohibere Vago : Sex and the Idiot Girl, 1846–1913. *Feminist Legal Studies*, *21*(1), 81–108.
- Stefánsdóttir, G. V. (2014). Sterilisation and women with intellectual disability in Iceland. *Journal of Intellectual & Developmental Disability*, *39*(2), 188–197.

- Stepan, N. (1985). Biological Degeneration: Races and Proper Places. In J. E. Chamberlin & S. L. Gilman (Eds.), *Degeneration. The Dark Side of Progress* (pp. 97–120). New York: Columbia University Press.
- Stoyanova, G. (2013, February 7). Forced Sterilization of Romani Women – A Persisting Human Rights Violation. Retrieved from <http://romediafoundation.wordpress.com/2013/02/07/forced-sterilization-of-romani-women-a-persisting-human-rights-violation>
- Taylor, A. (2015). The Discourse of Pathology: Reproducing the Able Mind through Bodies of Color. *Hypatia*, 30(1), 181–198.
- Taylor Gomez, M. (2012). The S Words: Sexuality, Sensuality, Sexual Expression and People with Intellectual Disability. *Sexuality and Disability*, 30(2), 237–245.
- Tonkiss, F. (2011). Discourse Analysis. In *Researching Society and Culture* (pp. 405–423). Sage.
- Wilfond, B. S., Miller, S., Korfiatis, C., Diekema, D. S., & Goering, S. (2010). Navigating Growth Attenuation in Children with Profound Disabilities. *Hastings Center Report*, 27–40.