

‘I’M THE MOTHER’: EXPERIENCES OF MOTHERS AND FATHERS WITH DISABILITY IN CHILE

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ABSTRACT. People with disability (PWDs) are often infantilized and regarded as asexual and ‘non-reproductive’. As a result, their parental processes and experiences are invisibilized or violated. In the framework of a qualitative study conducted in Chile, 20 in-depth interviews were conducted with mothers and fathers with physical, sensory or intellectual disability. The social environment of people with disability questions their ability of being mothers and fathers using eugenic and disability arguments. Once they have children, the combination of surveillance, lack of support, and barriers puts them in a very vulnerable position. Both mothers and fathers develop resistance strategies to counteract negative views about their disability and avoid discrimination in a hidden effort that has a high emotional and physical toll on them. The motherhood and fatherhood of people with disability can be seen as a resistance strategy in itself since it allows us to understand that there is no contradiction between caring for another and needing care.

Keywords: Parenthood; disability; discrimination.

‘A MAMÃE SOU EU’: EXPERIÊNCIAS PARENTAIS DE MÃES E PAIS COM DEFICIÊNCIA NO CHILE

RESUMO. Pessoas com deficiência são frequentemente infantilizadas e consideradas assexuadas e não reprodutivas. Isso faz com que seus processos e experiências parentais se tornem invisíveis ou violados. No âmbito de uma pesquisa qualitativa, foram realizadas 20 entrevistas em profundidade com mães e pais com deficiência –física, auditiva, visual ou intelectual/cognitiva—no Chile. O meio social das pessoas com deficiência questiona suas possibilidades de serem mães e pais por meio de argumentos eugênicos e de incapacidades. Depois de terem filhos, a combinação de vigilância excessiva, falta de apoio e barreiras torna a posição de mães e pais muito vulnerável. Mães e pais com deficiência desenvolvem estratégias de resistência para neutralizar visões negativas sobre a deficiência e evitar a discriminação, o que envolve trabalho oculto que tem um alto custo emocional e físico para eles. A maternidade e a paternidade das pessoas com deficiência podem ser vistas como uma estratégia de resistência por si só, uma vez que permitem compreender que não há contradição em precisar de cuidados e cuidar do outro.

Palavras-chave: Parentalidade; deficiência; discriminação.

‘LA MAMÁ SOY YO’: EXPERIENCIAS PARENTALES DE MADRES Y PADRES CON DISCAPACIDAD EN CHILE

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RESUMEN. Las personas con discapacidad (PcD) suelen ser infantilizadas y consideradas como asexuadas y no reproductivas. Esto ha llevado a que sus procesos y experiencias parentales sean invisibilizados o violentados. En el marco de una investigación cualitativa se realizaron 20 entrevistas en profundidad a madres y padres con discapacidad - auditiva, visual, física, intelectual- en Chile. El entorno social de las PcD cuestiona sus posibilidades de ser madres y padres utilizando argumentos eugenésicos y de incapacidad. Una vez que tienen hijos(as) la combinación de la sobrevigilancia, la falta de apoyo y las barreras hace que la posición de madres y padres sea muy vulnerable. Madres y padres con discapacidad desarrollan estrategias de resistencia para contrarrestar las visiones negativas sobre la discapacidad y evitar la discriminación, lo que conlleva un trabajo oculto que tiene un alto costo emocional y físico para ellas(os). La maternidad y paternidad de personas con discapacidad puede ser vista como una estrategia de resistencia en sí misma ya que permite comprender que no existe una contradicción entre cuidar a otro y necesitar cuidado.

Palabras clave: Parentalidad; discapacidad; discriminación.

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (Organização das Nações Unidas [ONU], 2006) establishes that all people with disabilities (PWDs) have the right to freely and responsibly decide the number of children they want to have and be granted access to reproductive and family planning information. However, PWDs tend to be infantilized and considered asexual and 'non-reproductive' (Bertilsdotter Rosqvist & Lövgren, 2013; World Health Organization [WHO], 2014;). Therefore, their reproductive processes and experiences have been violated and made invisible. The violation of the reproductive and parental rights of PWDs is expressed in several forms: lack of support for their needs in the health care system, loss of custody of their children, loss of parental rights, inability to adopt and forced sterilization (without free and informed consent) (Parchomiuk, 2014; Frederick, 2017b).

The negation of parenthood is based on two arguments: first, the questioning of their parenting capacities and second, eugenic discourses assuming that PWDs will have children with disabilities and that this will be a burden for society (Prilleltensky, 2004; Malacrida, 2009; Frederick, 2017a; Servicio Nacional de la Discapacidad [Senadis], 2018).

The purpose of this article is to explore how the meanings associated with disability impact the parenting experiences of people with disabilities in Chile. Parents with disabilities undertake two roles that are often seen as opposite: care givers and receivers. They continuously have to navigate between these two roles and face the barriers and stigmatization imposed by their environment and society (Malacrida, 2007; Drew, 2009).

This article seeks to contribute to the discussion about parenting and disabilities by 1) Analyzing the stories of a group traditionally excluded from reproduction (PWDs); 2) Including the stories of men with disabilities, since most studies on reproduction focus on women's experience, overlooking the male experience (Miller, 2011; Herrera, 2013; Herrera & Pavicevic, 2016); 3) Recognizing the local context in the construction of parenting in a country out of the European and North American framework. Research on this topic is very scarce in Latin America and even more so in Chile (Cruz Pérez, 2015; Pérez-Bolívar, 2016).

Intensive parenting in Chile

Research in the field of Parenting Culture Studies (Gürtin & Faircloth, 2018) has identified a tendency towards the 'intensification of parenting' over the last decades, which is expressed through increasing demands on parents, especially on mothers (Hays, 1996). In general, contemporary parenting is becoming an extremely conscious activity, which requires full-time commitment and a great investment of economic, social and emotional resources. Parent authority is undermined because their experience is no longer enough to raise their children, and it is expected that they inform themselves based on expert and scientific knowledge (Faircloth, 2014; Gürtin & Faircloth, 2018). According to Frederick (2015, 2017a), the expectations for mothers have never been as high, expecting them to 'perform' a perfect version of motherhood.

There is evidence that parents are also subject to increasing requirements, needing even more support because they would not have the 'natural' predisposition for child rearing attributed to females (Faircloth, 2014). Parents that cannot or do not want to comply with the standards of intensive parenting put at risk the bond with their children since the State intervenes, questioning their parenting skills (Gillies, 2008). In the framework of contemporary family diversity, these phenomena would affect all family configurations, and to a larger extent in monoparental households with females heads or vulnerable and minority groups, which are particularly monitored and penalized by the State (Frederick, 2015, 2017a; Gillies, 2008; Malacrida, 2009; Salvo Agoglia, 2016; Herrera, Salvo Agoglia, & Campos, 2020).

In Chile, this intensification has been linked to neoliberalization contexts where work conditions are more unstable and support from the State is limited (Vergara, Sepúlveda, & Chávez, 2018). In a context with structural conditions of inequality, public policies for childhood have focused on mothers (overlooking community measures or measures with a gender perspective) (Calquin, Guerra, & Vásquez, 2020). Likewise, the early childhood welfare system has designed interventions—oriented to the promotion of breastfeeding, early stimulation and 'active' child-rearing—focused on a normative and hegemonic ideal of motherhood that does not embrace the plurality of the existing models of motherhood (Calquin et al., 2020).

According to the studies conducted by Murray (2013, 2015) and Vergara et al. (2018), in Chile, the standards for parents have increased and they are now responsible for the 'failure' of their children. The exercise of motherhood revolves around surveillance and suspicion. Mothers who participate in the early childhood welfare system feel monitored and controlled (Calquin et al., 2020). All the real or imaginary problems of their children are explained by the actions or omissions of their parents, with mothers considered as the main responsible person for any 'fault' or 'flaw' of children (Vergara et al., 2018).

Social research has barely explored how this new culture of 'intensive parenting' specifically affects 'other diverse families' such as families formed by parents with disabilities (Herrera et al., 2020).

Parenting of people with disabilities

We live in societies where pro-birth is selective. States encourage reproduction in specific family models (two white, middle-class providers) (Bertilsdotter Rosqvist & Lövgren, 2013) through policies and laws that build an ideal mother/father model (Blackford, 1993).

This model is incarnated by people without physical, intellectual or sensory limitations. In this framework, PWDs are not considered as suited for parenthood (Blackford, 1993). Along the last century, parenting has been denied to PWDs through sterilization, institutionalizations and discriminatory adoption norms (Björnsdóttir, 2013; Tilley et al., 2012). Having children is considered a central experience for the development of adult life (Bertilsson Rosqvist & Lövgren, 2013; O'Dell, Brownlow, & Bertilsson Rosqvist, 2018), but PWDs are not considered reproductive (Slater, Ágústs dóttir, & Haraldsdóttir, 2018).

Parchomiuk (2014) proposes addressing the parenthood of PWDs from the disability social model (Oliver, 1999; Barnes, 2007), i.e., to analyze how environmental factors and social attitudes towards disability affect quality in the parenting by mothers and fathers with disabilities. From childhood, PWDs often receive a 'socialization for disability' in their families and educational institutions. Consequently, they develop a 'disabled' identity, with a self-image dominated by limitations (Parchomiuk, 2014). In the socialization process, PWDs internalize the idea that they are 'asexual', non-reproductive people, and unable to take care of others. Considered 'asexual', PWDs do not receive sex education nor information about the prevention of sexually transmitted infections (Bertilsson Rosqvist & Lövgren, 2013; Cruz Pérez, 2015). This causes many women with disabilities have to explain their motivations to be mothers or that they doubt whether they could be 'good mothers' (Prilleltensky, 2003). The parenting by PWDs is usually disregarded (Prilleltensky, 2003; Parchomiuk, 2014) and considered a transgression (O'Dell, et al., 2018). The reproductive intentions of this population are discouraged by means of biomedical discourses (such as genetic inheritance or fetal damage).

Mothers with disabilities feel that family and professionals question their capacity to rear children (Pérez-Bolívar, 2016). If they become pregnant, it is common that this is considered an irresponsible action because a 'defective' genetic predisposition could be transmitted, and these mothers will never reach the high standards of intensive maternity (Hays, 1996). Mothers with disabilities are subject to monitoring and scrutiny by the health and education systems (Frederick, 2015, 2017a; Malacrida, 2009). During pregnancy, they are often recommended to abort or give their child up in adoption (Walsh-Gallagher, Sinclair, & Mc Conkey, 2012; Frederick, 2015). Health professionals often take a welfarist approach, in which pregnant women are seen as patients that are dependent, passive and victims (Walsh-Gallagher et al., 2012; Höglund, Lindgren, & Larsson, 2013; Cruz Pérez, 2015). These professionals usually contact social services and activate surveillance devices in which disability becomes the central argument to question the capabilities of PWDs in taking care of their children (Frederick, 2015; Walsh-Gallagher et al., 2012). Mothers with disabilities feel that their right to make decisions and have control over their reproductive and parenting experiences is not respected (Cruz Pérez, 2015; Redshaw, Malouf, Gao, & Gray, 2013; Walsh-Gallagher et al., 2012).

Health services are conceived and designed for 'normative' bodies, not being adapted to the needs of PWDs (Walsh-Gallagher et al., 2012). The same occurs in educational and recreational establishments, where parents with disabilities face significant barriers to participate in the lives of their children.

Surveillance is increased if parents belong to any other group marginalized due to social class, ethnicity, sexual orientation or religion. A mother with disabilities who belongs to an indigenous or impoverished group that does not meet the high expectations for intensive parenting has high possibilities of alerting State institutions and facing serious threats to her parental rights. In the case of mothers with intellectual disabilities, Strnadová, Bernoldová, and Adamčíková (2018) argue that they tend to be poor and face prejudice and

negative attitudes towards their maternity from professionals and family. This usually leads to the removal of children from their care, even when these women can fulfill the role of mother with adequate support. Bertilsdotter Rosqvist and Lövgren (2013) believe that, in these cases, excessive surveillance is combined with access barriers and a lack of support. A study about parents with disabilities conducted in the USA revealed that 6.2% of people with children live with some disability (4.1 million parents). These people are more likely to have low income, be women, and have less education and worse health than their peers without disabilities. The study concludes that systematic discrimination against these parents contributes significantly to these differences (Li, Parish, Mitra, & Nicholson, 2016).

Frederick (2017b) proposes that mothers with disabilities develop daily resistance strategies to counter the negative views about their disabilities. These strategies range from presenting a highly disciplined public image of motherhood ('super moms' that incarnate the values of intensive mothering) to avoidance and distancing practices that allow them to shut down any possibility of being assaulted (anticipating discrimination). The development of these strategies takes a high emotional and physical toll, as mothers with disabilities have to work hard so their efforts are not noticed by their social environment (Frederick, 2017b). Likewise, strategies developed for resisting stigma vary according to social class and privilege.

Methodology

The findings presented in this study are based on the first results of a qualitative research that is been conducted in Chile, whose objective is to study how the meanings associated to disability influence the parenting experiences of women and men with disabilities. These elements cover the following elements of inclusive research: i) to research with the participants and not about the participants, ii) all the decisions made in the study consider the needs of its participants (making all the adjustments and adaptations necessary), and iii) topics relevant to the participants are explored (Rix, Carrizosa, Seale, Sheehy, & Hayhoe, 2019; Nind, 2017).

At the time of writing this article, in-depth interviews were conducted with 20 parents with disabilities. All interviewees were requested to narrate how they had lived the parenting process. This request led to a free-speech where interviewees organized and gave meaning to their experiences. The structure of the interviews was flexible and fluid, which allowed addressing unexpected topics (Mason, 2002).

Researchers are part of the world that unfolds during research (Cruz, Reyes, & Cornejo, 2012) and their identity is inseparable from the research process. Therefore, autobiographic interviews were conducted with the members of the research team: the main researcher (author of this article), sociologist and mother with visual disability, Luis Vera Fuentealba, sociologist and father with visual disability and Valentina Arriagada, sociologist without disabilities nor children.

The interviews were conducted at the homes and workplaces of the interviewees, as well as in some public places (coffeeshops and parks). The 5 last interviews were conducted in the context of the COVID-19 crisis and therefore were remote, specifically through videoconference. Average interview duration was one hour. All interviews were recorded and transcribed.

Participants were recruited through social media, personal networks of the research team and foundations linked to disabilities. People interviewed also suggested potential participants (snowball technique) to the research team. The research team tried to reach out to people with

different profiles to portray a wide range of experiences of parents with disabilities. Eleven mothers and 9 fathers were interviewed. Of the participants, 8 had physical disabilities, 5 were deaf, 5 presented visual disability and 2 intellectual or cognitive disabilities. Some participants' disabilities were genetic, while others were product of accidents or disease. In some cases, the condition was detected at birth, or early childhood, and in others it developed along their life. When necessary (6), a sign language interpreter or someone trusted by the interviewee assisted during the interview. The age of participants ranged from 25 to 50 years of age at the moment of the interview. Participants had different schooling levels (from absence of formal education to postgraduate studies). The situation of their partners was also diverse: some people were married to the father/mother of their children, while others were separated/divorced, living together. There were also mothers who had no contact with the father of their children. Most children were not planned and were aged less than 8 years at the moment of the interview.

Thematic content analysis was employed to analyze the interview transcripts. This involved identifying and coding the most significant fragments of the interviews that aligned with the objectives of the study (Atkinson & Coffey, 2005; Ruiz, 2009). The category or code system was inductive. Most codes were created based on the transcripts of the interviews. The study was approved by the Ethics Committee of Universidad Diego Portales. Participation was informed, voluntary and confidential. Pseudonyms were used to protect the identity of the people interviewed.

Results

I. Stigmatization of disability and parenting experiences

a) Before having children

Participants indicate that before having children, their social environment questioned if they were able to be parents. In their stories, this questioning is based on two arguments. The first one is eugenic: you should not have children because your children will have disabilities. Several interviewees, especially those with a genetic condition expressed that physicians from different specialties told them they should not have children. Rafael (father with a physical disability) narrates that when he was an adolescent, a female physician told him that he should not think of the possibility of becoming a father because he could have children that inherited his 'disease':

When I was 15, I was diagnosed and roughly at that time I was told that I should not have children because I should not pass on harmful genes to another person [...] This female doctor, a rheumatologist, tells me that I shouldn't even think of becoming a dad because I had a genetic disease and shouldn't bring children with a disease into this world [...] It hits you, it stays with you forever, I remember what she told me to this day.

The second argument questions the parental skills of PWDs: you should not have children because you are not going to be able to take care of them properly. Specific questioning varies depending on the type of disability. If interviewees have a sensory disability, it is thought that they will not be able to identify the needs of the baby. If the disability is physical, they would not be able to respond to the needs of the child. In the case of an intellectual disability, it is assumed that PWDs will not be able to take control and be responsible for the child, and that they might even do things that put the child at risk. This is consistent with studies conducted in Spain and Canada (Prilleltensky, 2003; Pérez-Bolívar, 2016), which indicate that mothers with disabilities feel that their child-rearing skills are

questioned by family and professionals. Karen (mother with a visual disability) narrates the reactions of her family when she mentioned the possibility of becoming a mother:

Taking the decision of becoming a mother in this way, with a disability, is questioned by everyone. I never questioned it myself, but everyone does, 'what are you going to do if the kid gets sick, how are you going to travel far from here with him, how are you going to know if something happened to him', and all that [...] Aunts, cousins, everyone, 'how are you going to do this, how are you going to do that, if it is hard for us, it's going to be even harder for you ...'.

Carolina (mother with a physical disability) narrates that before delivery, a physician threatened to take her baby away from her as soon as she was born, arguing that she would not be able to take care of her. Here the alleged contradiction between taking care of and being taken care of becomes explicit:

This doctor comes and stares at me because he came with some students, and he stares at me and shakes his head, and then he starts yelling 'but how is it possible! In your condition! Look at yourself! How dare you become a mom?', I don't know, 'your daughter is not going to leave this place because as soon as she's born, I'll take care of her'. He told me his full name and said 'your daughter doesn't leave with you, because look at you, you can't even get changed on your own, nor take care of yourself', something like, 'you can't even change your own diaper', something like, 'and you are going to take care of a girl' and ... attack after attack, I had my first panic attack.

This questioning generates that PWDs find it hard to make the decision of having children. Most people who participated in this study did not plan to become parents (especially mothers). In the words of Bernardo (father with a visual disability), it is observed that he internalized the eugenic argument. His story presents disability as 'a burden' that should not be passed to the next generation. Deciding to become a parent is considered a selfish decision:

I always questioned the possibility of becoming a parent, always. Because of the possibility of passing the disease and that it affected someone else besides me. That is to say, it's like a lottery and I am being selfish in wanting to be a dad...having to give that burden to someone else.

Carolina (mother with a physical disability) expresses that she internalized the stigma associated with disability from her family, and therefore when she became pregnant, she had to face her own prejudice:

You grow up in society and family with imposed rules, in other words, what you can do and cannot do. What is normal and what is abnormal for a woman with disabilities. Then, that a woman with a severe disability like me becomes a mom is socially unacceptable. It is crazy, insane, and well, I grew up with...I grew-maybe I could accept it for another woman, but not for myself. So, I clearly saw it as a failure, one more failure in my life.

The stigmatization of disabilities has very concrete effects on the parental experiences of PWDs. The socialization of disabilities creates a 'disabled' identity, with a self-image dominated by limitations (Marszalek, 2006; Parchomiuk 2014). Women and men internalize this stigma, and it becomes difficult for them to believe they could be 'good mothers' or 'good fathers'.

b) After having children

After their children are born, the interviewees have to make efforts for their social environment to acknowledge them as parents. Many participants report having suffered strong pressure to delegate the care of their children to other family members (mainly

grandmothers). Marcela (mother with an intellectual disability) explains that when she became pregnant, her mother assumed she should have to take care of the baby.

Marcela: After I became pregnant, problems started. That's when problems started.

Interviewer: What were the problems?

Marcela: The problems my mom said, 'uh you're going to have a baby, and I'm going to have to go with you everywhere' (laughs).

Support assistant: Your mom thought she would have to do everything.

Marcela: Yes and I told her 'No, things are not like that, I'll do the things, you're not going to do them'. 'Yes, but then the baby is going to start crying and won't let me sleep', 'well, you can't do anything but put some cotton balls in your ears' (laughs).

Health professionals also reinforce the stereotype that a woman with disabilities will not be able to take care of their children and will have to delegate their care. Rosario (mother with a visual disability) tells the interviewer that when she was still in hospital after her second son was born, health professionals insisted that she had someone else helping her to go back home with her new baby. They kept insisting even when Rosario told them that she did not need help. The fact that Rosario is blind makes it difficult to acknowledge that she may have knowledge and expertise in childcare:

They asked for someone to go help me with the baby, who stayed with me there. And I told them no, that I didn't have any problem because I already had a daughter, but they kept insisting. Until a nurse told them 'Let her, she already has a daughter, she already knows what she's doing' [...] Because they believe that a blind person is not able to, I don't know, change diapers, dress their children, because they believe you can harm them ...

In the stories of participants, after their children are born, the questioning of their parental skills is followed by monitoring of their care practices. Particularly, mothers feel constantly controlled and evaluated by family and health professionals. This leads them to constantly proving that they are 'good mothers'. Mysaki (deaf mother) reports that she had to confront her parents to take back her role as a mother and main caregiver of her son:

My mom comes and tells me 'Why didn't you change the baby?' And I know, the milk, the food, 'mom, leave me alone, I know, I'm responsible, don't control me so much'. Until one day I got mad, I got upset at my mom and I told her how I felt. They thought my son was going to be like my brother, that I was going to withdraw my responsibility of taking care of my child. It was a critical time, of crisis.

Even when control is much stronger over mothers, fathers also suffer the effects of being considered 'incapable' of taking care of their children. In the case of fathers, family concerns exclude them due to their disabilities and their sex. Rafael (father with a physical disability) expresses that the attitude of his family is an obstacle for him to take a more active role in the rearing of his son: "They have always tried to minimize the responsibility that I have with my son. Putting into question, let's say, if I was able to stay with him on my own, to feed him".

In some cases, control and surveillance progress into constant suspicion that parents will harm their children. Marcela (mother with intellectual disability) has had to confront health professionals and family courts to keep the custody of her daughter. In different occasions, she has been accused of neglect and abuse. Accidents that may occur in all homes are interpreted as intentional in these cases. Marcela is a very apprehensive mother who takes her daughter to hospital for even minor discomfort. This plays against her as it thickens the medical record of her daughter, which is then used against her in court. In the following date, Marcela tells the interviewer that her daughter suffered a small burn, and she

was accused of burning her: "I showed her [the burn] they blamed it on me, and I didn't do it. It wasn't me-if I had burned my daughter, I would have blamed myself. I didn't do it. If it were me, I would have admitted it".

The immediate environment may play a 'disabling' role. For example, overprotecting grandparents may limit the parental practice of their children. Fernanda (mother with a physical disability) tells that since her parents see her as incapable, it has been easy for her to let go and let her parents bring up her daughter. In the interview, she complains that her daughter does not respect her as a mother.

In other words, I have also taken a very comfortable position in which 'ok, you don't want me to change her diaper? I won't do it, do it yourself, you don't want me to cook for her? Ok, I won't, do it yourself'. Now this is weighing on me in terms that there's zero respect to me. I'm basically my daughter's older sister.

Atila (father with a physical disability) argues that his family and wife have always tried to make his life easier. However, this concern for him has made it more difficult to assume his responsibilities as a parent:

I am spoiled by all people, can you imagine...I think that, throughout my life, I don't know, my mom, everyone at home have made things easier for me...so they have made many things easy, in the end...they...limit you...it is impossible for you to do some things.

In addition to the difficulties parents face by internalizing negative stereotypes about disabilities, they also encounter environments that many times are not willing to make reasonable adjustments to allow them to exercise their parenting. Cynthia (deaf mother) narrates that throughout her delivery process, she did not have access to a sign language interpreter. In other words, she could not be informed not make decisions about her own health and her son's health:

There was no communication in the hospital, so everyone (else) made decisions [...] The doctor and medical team did not provide much information. The resident in that hospital helped me understand what was happening to me, because the medical team was not telling me what was going on. [...] No, the doctor barely communicated with me, barely, he only was writing his report. When the resident read it, she informed me. And there was no communication at all, only gestures, some gestures, so for example, I turned my wrist because they had to put me a catheter. Or they asked me to move a bit to the side, or to pull my clothes up. Or touched me to know how dilated I was.

Fernanda (mother with a physical disability) shares that when going to the hospital with her little daughter, they would not let her enter with her mother (grandmother of the girl) because the norm establishes that only one person can enter per child. The option she was given was to let her mother enter with her daughter and waiting outside.

I told her 'I can't grab the bag, plus the girl, plus everything' [...] 'then the grandma can stay', and I told her 'You're depriving me from the possibility of taking care of my daughter because I have a disability' [...] it was as if (she was saying) 'if you have a disability and can't do it, leave'.

The stories of Cynthia and Fernanda are examples of how the lack of reasonable adjustments makes mothering difficult and forces mothers to delegate care to other people. This violates their rights as mothers and also the rights of their children. The devaluation of parenting by PWDs negatively affects their parenting experiences. It makes it difficult for them to make the decision of having children, and when they have them, they have to make efforts to be respected as mothers and fathers. The environment, rather than being

accessible and inclusive, is reluctant to make reasonable adjustments or adaptations. This makes parenting even more difficult.

II. Resistance strategies

As in the study by Frederick (2017b) on mothers with disabilities in the USA and Canada, both mothers and fathers interviewed develop daily resistance strategies for countering the negative views on disability and protecting themselves from discrimination. Some of the strategies identified are presented below:

a. Respectability politics: Presenting a highly disciplined public image to challenge negative stereotypes. The use of this strategy is very evident in the interviews with mothers. Mothers, compared to fathers, do not mention having difficulties in the daily exercise of childcare; instead, they deny that their disability limits them in the exercise of their mother role. The difficulties and limitations they mention are external, imposed by the environment. For example, Rosario (mother with a visual disability) argues that she did not have any problems to take care of her newborn daughter: "And I didn't have any problem with the C-section, nor with taking care of her. But doctors feel conflicted, they told me someone needed to be with me". Karen (mother with a visual disability) expresses that being a mother with disability is nothing special and emphasizes that mothers with disabilities are excellent mothers:

I don't see the relation, for example, between being a mom with or without disability. For me, being a mom is just being a mom, it's living it [...] I saw many cases of mothers with other types of disabilities that managed very well, you know? And they were excellent moms, so to me, being a mom with or without a disability was never an issue that affected my life, I didn't... I saw it in a very natural way. Because other people take it as if it 'is so complicated for her to be a mom that way ...' And for me it's not, it wasn't in any way. [...] I also know a lot of moms who are blind and have never seen. Never, and they manage super well, and I think they're much more responsible for their children than other moms ...

It would be hasty to conduct a literal reading of the words of the interviewees and conclude that mothers with disabilities do not face obstacles in the rearing of their children. As a mother with a visual disability, I have no doubts that blindness or low vision pose challenges and difficulties in daily childcare. My interpretation is that women do not allow themselves to talk about these difficulties because they feel the high demands of the environment and know they are surveilled and looked at with suspicion. Voicing these obstacles may threaten their relationship with their children (Frederick, 2015, 2017a; Gillies, 2008; Malacrida, 2009). Therefore, they seek to project a very competent image: a 'super mom' that can perform autonomously all the tasks associated with childcare (and with intensive maternity). In this way, they protect themselves from the surveillance and intervention of the State.

b. Disengagement politics: They consist of preventing and avoiding situations in which some stigmatization or discrimination is foreseen. This also leads to hiding or dissimulating the own disability or not responding to aggressions. For example, Gloria (mother with achondroplasia) avoids going to a neighborhood where people have mocked her, yelled insults at her or taken pictures of her without her consent. Cynthia (deaf mother) does no longer go to parent meetings due to the lack of support in the kindergarten (the grandmother goes instead). Paula (mother with a physical disability) expresses that fighting is worth it sometimes, while other times, she prefers to go unnoticed and spare herself unpleasant moments:

It's as if people believe that because you're in a wheelchair you know nothing [...] they ignore you, and [I tell them] 'why are you ignoring me?' But sometimes I tell them, and other times I just don't say anything. [...] or sometimes you have no option but to give in... for example, when I go to hospital, everyone is very nice to me, but sometimes, when there's someone who doesn't know you and [is not nice to you], well, why pick a fight with her.

c. Visibility politics: These strategies may be divided into two: i) confrontation and ii) education.

i) Confrontation: This strategy consists of confronting people who are discriminating and demanding the rights that are not being respected. This strategy implies great emotional involvement and takes a significant toll. Carolina (mother with a physical disability) narrates a conversation she had with an authority from the State. Carolina was requesting more support to have personal assistance and travel to her daughter's medical check-ups in Santiago, where specialized medical services are:

[...] and they told me, 'But Caro, you really do not accept your own disability, you're asking for too much, with my own daughter who has a disability [...] I don't take her out of our home, we don't go on vacation with her'. And I got angry. Truly, they made me fly off the handle and I went on a rant, without any coarse language by the way, I was very polite, but I told them everything as politely as possible.

In this case, Carolina confronted an authority who tried to impose a limitation-centered view of disability. In the previous section, I presented the case of Cynthia (deaf mom) who did not have a sign language interpreter during delivery. Cynthia felt discriminated and abused. She describes herself as shy and easily embarrassed, but states that when she had her baby, she realized that she would have to fight for her and her son's rights. She decided to demand a sign language interpreter and when she arrived, she threatened with reporting the case to the Ministry of Health:

Then I told them that I really needed an interpreter because I was feeling very bad, that there was no information for me, my son was downstairs with his eye swollen, my wound was infected, and nobody would explain anything to me. My sister told me little, didn't understand anything. So, I wanted to get official information, to have explained what was going on. [...] I told [the midwife through the interpreter] 'I'm really upset, I have not been given proper information because they think that since I am deaf then they should tell me less. No, I want clear information and know why, what is happening to me, why I have an infection, is it the doctor's fault to have the wound infected, did my body cause this? My son as well, the swollen eye, inflamed, what happened??' [...] So 'you think that because I'm deaf I am worth little? You still have to respect me, how is that people who can hear are respected and I'm not? I'm not a monkey, I'm not an animal, I'm a human being, respect me, I have the same rights as any other person. If you upset me again, I'll report you to the Ministry of Health'. I threatened them. The interpreter did all this, the interpreter with a voice like mine, that is, I saw the interpreter was showing I was mad.

ii) Education: this strategy implies becoming present and visible in the environment without disabilities in order to inform and educate. Carolina (mother with a physical disability) has assumed the roles of educator and disability rights activist and launches information campaigns on social media, in which her situation is represented.

Yes, generally at night, I dedicate time to my maternity [and disability] space and social media, in order to show or report on maternity, the shortcomings, inclusion in this topic, I communicate with some moms to give them information, support, and to share experiences.

When he has faced discriminatory attitudes, Martín (deaf father) has been patient and explained how he deals with the difficulties of child-rearing. In this way, he counters the stigma that presents disability as a limitation for caregiving tasks:

Once I was told 'you can't have children, because babies cry, and you, how are you going to hear that your baby is crying, for instance, at night when you're asleep? And I explained to him that I have a tactic, a strategy [...] Few people believe that a deaf person can be a dad, most think that it is not possible, or that it's really hard, or sometimes that deaf people can put their children for adoption.

According to Frederick (2017b), the practice of visibility politics implies spending much emotional energy. Visibility politics put parents in contact with an environment free of disability that is usually not accessible or sensitive to their needs. Parents with disabilities should become strong to deal with negative reactions and develop a series of strategies to handle aggression. The energy spent in anticipating aggressions, planning response strategies and handling stigma often remains invisible for most people without disabilities.

The decision of having children and exercising parenting may be seen as a resistance strategy. Whether by deciding to have children or assuming an unplanned maternity/paternity, these parents resist the dominant ideas that people with disabilities should not have children (Frederick, 2017b). Having children in the knowledge that they could inherit their parents condition is an act of resistance against eugenic ideas, which assert that that only 'healthy' people should reproduce. Bernardo, who initially questioned the possibility of becoming a father due to the fear of his son having a visual disability, expresses how he changed his mind by recounting a conversation he had with his wife before deciding to have children:

'What if we have a child?' And the conversation was like 'well, what if he has the disease?' 'Well, I'll have to teach him. If he has the same disease I have, I will have to give him all the tools I have acquired and built so that he can go further than me'.

Here Bernardo changes his approach on disability. He does not consider it a burden anymore, and does not see the decision of having children as selfish. He focuses on his strengths as a father: if his son has a visual disability, he will be able to teach him and support him. Bernardo, who did not have blind people in his family to guide him, considers that his son would be in a better situation if he developed a visual disability. He starts seeing himself as a person who can contribute to the development of his son and not as someone who should not reproduce.

Final considerations

The increase in child-rearing demands (intensive parenting) and the understanding of disability as a personal tragedy create a complex scenario for PWDs who want to have children or that already have them. PWDs find it hard to see themselves as parents and decide to have children. Their social environment questions their possibilities of becoming parents using eugenic and disability-related arguments (Prilleltensky, 2004; Malacrida, 2009; Frederick, 2017a). PWDs internalize these arguments, are afraid of passing their condition to their children and fear being unable to take care of them. Most interviewees had unplanned children. Once their children are born, mothers feel that their social environment put pressure on them to delegate childcare. There have even been some cases of attempts to take custody away from them. The combination of excessive surveillance, lack of support and barriers puts parents in vulnerable positions. This is especially dramatic in the case of mothers (Bertilsson Rosqvist & Lövgrenb, 2013).

Parents with disabilities develop strategies for resisting the stigmatization and discrimination that affects them and their children. These strategies are coincident with the ones identified by Frederick (2017b) and are associated with respectability (to project a

highly disciplined image according to intensive maternity), avoidance (to avoid situations where discrimination is foreseen) and visibility politics (to confront discriminatory attitudes, educate and inform about the rights of PWDs). These strategies imply anticipating discrimination, planning how to avoid it or confront it, and effectively dealing with it daily. The maneuvers of parents to cope with stigma and discrimination entail a work that remains hidden to the disability-free environment, leading to high emotional and physical costs (Frederick, 2017b).

The preliminary results of this study allow for identifying some key aspects for intervention: a) 'Socialization for disability' needs to end. PWDs should be educated as sexual and reproductive people (Parchomiuk 2014); b) Healthcare professionals should be informed and educated to focus on the capacities instead of the limitations of PWDs (Redshaw et al., 2013); c) Necessary support and adjustments should be ensured so parents with disabilities can keep control of their parenting; d) Parenting skills of PWDs should not be evaluated based on the ability to perform practical and daily tasks but on the capacity to act and make decisions responsibly (Prilleltensky 2003; Parchomiuk 2014); e) Childhood support systems should not be designed based on a normative parenting model (with high demands). These systems should have a more community-focused approach and accept the existence of different forms of being a parent. Everyone needs help and has limitations. Nobody is capable of bring up a child on their own.

Some aspects that would be relevant to address in future research are: a) to study how social class, education and privilege or marginalization influence the use of different resistance strategies (Frederick, 2017b); b) to analyze how different gender-related expectations and requirements affect the parenting experiences of mothers and fathers with disabilities; c) to research the experiences of PWDs' children (Prilleltensky, 2004; Malacrida, 2009; Drew, 2009).

The parenting exercised by PWDs may be understood as a resistance strategy, as it counters the view that people with disabilities are childish, passive and victims. The fact that people with disabilities become parents allows for understanding that there is no contradiction between needing to be cared for and taking care of others. Everyone takes care and is taken care of by others (Borneman, 1997). Collective life is sustained by that reciprocity.

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